Title: HIV disclosure in the workplace among people living with HIV/AIDS in Nigeria

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HIV DISCLOSURE IN THE WORKPLACE AMONG PEOPLE LIVING WITH HIV/AIDS IN NIGERIA

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HIV DISCLOSURE IN THE WORKPLACE AMONG PEOPLE LIVING WITH HIV/AIDS IN NIGERIA

by

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D. I. ADEOYE

ABSTRACT

Background: HIV/AIDS is an infectious, chronic condition that may have several physical and psychosocial consequences for those affected (Peter, 2011). Advances in HIV treatment have improved the prognosis for people living with HIV/AIDS (PLWHA) and their overall health. As a result, PLWHA can be employed for longer whilst they manage their condition. There is evidence that people with infectious diseases, and especially HIV/AIDS, are being stigmatised. Stigmatisation or the fear of being stigmatised can affect the ways or whether the affected person would disclose their disease to their social or professional networks. There is currently very little known about disclosure in the workplace and especially for PLWHA who are employed in Nigeria.

Main aim: This research explores HIV disclosure in the workplace among people living with HIV/AIDS (PLWHA) in Nigeria.

Methodology: This study is into two phases: the first phase used a systematic review whilst the second phase a qualitative method. The systematic review collected and synthesised research-based evidence on HIV/AIDS disclosure in Nigeria. The qualitative approach used face-to-face semi-structured interviews with 20 employed PLWHA who had been diagnosed with HIV for more than six months before the time of recruitment in the study. The interviews were transcribed verbatim and analysed using thematic analysis.

Main findings: Fourteen studies (n=14) met the inclusion criteria of the systematic review. Twenty participants (n=20) were included in the qualitative study, both male (n=7) and female

(n=13) patients accessing HIV treatment from one hospital in Nigeria. The findings of the systematic review showed that following disclosure, a large number of respondents received support from their partners, while others reported negative reactions from their partners after the disclosure of their HIV positive status. These negative reactions included violence/assault, accusation of infidelity and divorce. Meanwhile, the qualitative findings show that PLWHA did not disclose their HIV status in the workplace and they remained in the 'default position of non-disclosure' because of the fear of being stigmatised, or because of concerns about their privacy and issues related to confidentiality. Some participants did not have the choice to decide whether they want to disclose in the workplace or not, because of reasons such as workplace regulation and policy, or running out of excuses. Those who disclosed their HIV positive status did so because they received workplace support/work adjustment. The workplace support/work adjustments include flexible work arrangements and requests for time off work to receive treatment in the hospital. HIV-related stigma, loss of job, and offensive remarks/gossip were reported as post-disclosure consequences in the workplace. This study showed that the reactions after HIV disclosure are not predictable both with their social or their professional networks.

Conclusion: Although, no generalisable conclusions can be made from this qualitative research, this study has provided an understanding of individual's perceptions and experiences in relation to HIV disclosure in the Nigerian workplace. This research has implications for policy, organisations and practice.

DEDICATION

In loving memory of my mother-in-law, Mariani Arike Ogundijo

1942-2017

DECLARATION

I, Dorcas Ibukun Adeoye, at this moment, declare this is my work.

To the best of my knowledge, it does not contain other previously published work, materials or images which have not been referenced either in text, reference list, bibliography, or in appendices;

Where I have quoted from the work of others, the source is stated. With the exception of such quotations, this thesis is entirely my work;

Any part of this thesis has not been previously submitted for a degree or any other qualification at this university or any other institution;

Phase one and some parts of phase two of this work have been published; copies of the abstracts are found in appendix 13 and 14 of this thesis, also listed on the 'peer-reviewed publication' page.

Name of Student: Dorcas Ibukun Adeoye Signature:

Date:

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PEER-REVIEWED PUBLICATIONS

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Adeoye-Agboola, D., Evans, & Pappas, Y. (Accepted) 'The implications of invisible symptoms in the pattern of disclosure among employed people living with HIV/AIDS in Nigeria', Qualitative Health Research

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CONFERENCE PRESENTATIONS

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LIST OF ABBREVIATIONS

AIDS- Acquired Immune Deficiency Syndrome

APA - American Psychological Association

ART- Antiretroviral Therapy

CDC- The Centre for Disease Control

CDCP - Centres for Disease Control and Prevention

CORAL - Conceal or Reveal model

CRD - Centre for Reviews and Dissemination

DPM - Disclosure Processes Model

DPT - Disease Progression Theory

FMLP - Federal Ministry of Labour and Productivity

HAND - HIV-associated Neurocognitive Disorder

HIV- Human Immunodeficiency Virus

IHREC- Institute for Health Research

KS - Kaposi's Sarcoma

NACA - National Agency for the Control of AIDS

NPHAS- National Policy on HIV/AIDS

OIs- Opportunistic Infections

OSH- Oyo State Hospital, Ogbomoso

PCP - Pneumocystis Carinii Pneumonia

PIS – Participants' Information Sheet

PLWHA- People living with HIV/AIDS

PMTCT- Prevention of Mother to Child Transmission

PPI- Public and Patient Involvement

PTSD - Post-traumatic Stress Disorder

SES – Socio-economic status

SOC- The Theory of Models of Selection, Optimisation and Compensation

SR-Systematic Review

STD – Sexually Transmitted Diseases

TPB- Theory of Planned Behaviour

UNAIDS - The Joint United Nations Programme on HIV/AIDS

UNDESA/PD- United Nations Department of Economic and Social Affairs/Population Division

US$ - United States Dollar

VCT- Voluntary Counselling and Testing

WHO- World Health Organisation

Chapter One: Introduction

This chapter presents the prevalence of HIV/AIDS globally and in Nigeria. It describes the burden of HIV to individuals, families, community, and workplace. It further explains how the burden of HIV is linked to stigma in general and specifically in the workplace. Furthermore, this chapter reviews the literature on how stigmatisation of people with HIV/AIDS may create a barrier to disclosure and explores the relevant theoretical model showing impact and consequences. Then, the chapter presents the aims and objectives of the study, methodology, and contribution to knowledge and finally, the last section shows the scope of the thesis.

1.1 Definition: HIV and AIDS

The World Health Organisation (WHO) describes the Human Immunodeficiency Virus (HIV) as a retrovirus affecting the immune system and creating impairment and destruction of defense systems (WHO, 2017). It transmitts via blood, unsterilised blood products, semen, cervical and vaginal secretions and breast milk (Aggleton and Homans, 1988; WHO, 2017). Following HIV infection, the immune system becomes weaker and susceptible to secondary infections, resulting in an advanced stage of HIV known as Acquired Immune Deficiency Syndrome (AIDS), and a period of severe disease lasting between 2-15 years resulting in death. The name, Acquired Immune Deficiency Syndrome (AIDS), is used to describe potentially life-threatening conditions caused by HIV as a result of a *deficient* immune system (Stolley and Glass, 2009). The progression of the disease depends largely on the immune system of the individual and the treatments available (WHO, 2017).

1.2 Epidemiology of HIV

Globally, the World Health Organisation 'WHO', (2017) reported that 36.7 million people were living with HIV at the end of 2016, 20.9 million people accessed antiretroviral therapy (ART) in mid-2017, and 1.8 million people become newly infected with HIV in the year 2016. The infection killed more than 1 million people in 2016, compared to 1.9 million in 2005 and 1.5 million in 2010 (WHO, 2017; UNAIDS, 2017; Ortblad, Lozano & Murray, 2013). Despite the

decline in the mortality of global HIV/AIDS, it remained the fifth leading cause of death globally (UNAIDS, 2017). The HIV prevalence varies across countries and it has a substantial impact on health-care budgets (Barnette and Blaikie, 1992). HIV/AIDS are also a major cause of death for some regions in the world such as Africa and central Asia (Lever and Wainberg, 2015). Ortblad, Lozano & Murray (2013) reported that Eastern and Southern Africa, Central Africa, the Caribbean, and Thailand fall within the regions that are most affected.

In the African region, more than 25.6 million people were living with HIV in 2016, amounting to approximately 70% of the global incidence (WHO, 2017). The number of AIDS-related deaths in Africa reduced by 39% between 2000 and 2016, as 75% of the infected population is receiving ART (WHO, 2017). In Africa, 1.4 million people were newly infected in 2014, representing a drop of 41% since 2000 (UNAIDS, 2015). South Africa is the worst affected country having over seven million people living with HIV/AIDS (PLWHA) in 2016 (UNAIDS, 2017). The majority of Africans infected with HIV are adults over the age of 25, especially young women (WHO, 2017).

The first case of AIDS in Nigeria was recorded in 1986, and HIV infection has continued to infect scores of the population in all parts of the country (National Policy on HIV/AIDS (NPHA) (2009). In 2016, The UNAIDS estimated more than 3 million people were living with HIV, and over 30% were accessing antiretroviral therapy (UNAIDS, 2017). In 2015, nine percent of the people living with HIV globally lived in Nigeria (UNAIDS, 2015), which indicates that Nigeria is a country with one of the highest burdens of HIV/AIDS. A report published by Awofala and Ogundele (2016) identified Nigeria as the country having the second highest prevalence rate of HIV in sub-Saharan Africa. The common routes of transmission include drug injection, unsafe sexual behaviour with less likelihood of condom use, conflicting and mixed messages around abstinence and condom promotion, and lack of sex education in schools, all contributing to the increase of the HIV epidemic and AIDS-related deaths in Nigeria (NPHA, 2009; Awofala and Ogundele, 2016). The part of the population mostly affected by HIV in Nigeria are sex workers (14.4%), gay men and men who have sex with men (23%), and people

who inject drugs (3.4%) (UNAIDS, 2017). New HIV infection in Nigeria has decreased by 21% since 2010, but the burden of HIV/AIDS remains (UNAIDS, 2017).

1.2.1 The burden of HIV/AIDS

HIV infection is a major public health concern that has claimed many lives worldwide (WHO, 2014a). The statistics are alarming, and the devastating impact of HIV and AIDS is felt globally (Kalichman et al., 2015). According to UNAIDS, about US$ 20.2 billion was invested in low and middle-income countries to tackle the HIV epidemic (UNAIDS, 2014). Individuals living with HIV/AIDS have been burdened in many ways by the disease. For example, the Nemakanga & Mndzebele (2015) study revealed that older adults living with HIV in northern Gauteng, South Africa experienced neglect, which consequently led to lower socioeconomic status and many psychological and physical challenges. Furthermore, there was less support among members of their families and communities due to the limited knowledge and understanding of HIV transmission. HIV infection can affect the mental health of people living with HIV as reported by a study in China (Niu *et al.,* 2016). People living with HIV are vulnerable to suicide attempts, stress, and substance abuse, while depression, anxiety, and stigma remain common problems faced by people infected with HIV (Niu *et al.,* 2016).

HIV infection is not only seen as a chronic illness affecting individuals but one that can also cause a substantial burden on the whole family (Komiti et al., 2001). For instance, studies (Chandran *et al.,* 2016; Lunberg *et al.,* 2016) show that the caregivers' burden includes a range of physical, emotional and financial challenges. In most developing countries, HIV infection increases the direct costs to the households of people with little social security (Poudel, Newlands & Simkhada, 2017). Hence, attention to the needs of an infected person can have a substantial impact on other family members' quality of life (Chandran *et al.,* 2016). For instance, infected individuals may be unable to do household work, so support is then needed from other people like family members, relatives or friends to care for them and assist them in their day-to-day activities (Poudel, Newlands & Simkhada, 2017).

A study (Mugisha *et al.,* 2013) in Uganda investigated the burden of people living with HIV/AIDS who are the main providers (breadwinners) in their households. It was found that these providers often lack the energy to continue to support their family members due to their illness: this limits their ability to care for their own health needs. However, these providers still perceive caring for their households as a duty (Mugisha *et al*., 2013). In a situation where the infected member of the family is the main provider, the total cost of treatment, as well as accompanying an infected person to a treatment clinic (for example, travel cost) result in a considerable financial burden on the main provider and the household in general (Poudel, Newlands and Simkhada, 2017). Meanwhile, HIV/AIDS remains a life-threatening and progressive chronic illness, and it has psychological, social and economic impact, affecting not only an individual and their family members but also their work productivity and performance (Nasidi and Harry, 2006).

UNIAIDS reported that young people (between the ages of 15-49 years) are more infected with HIV, which may lead to serious economic implications (UNAIDS, 2015). It has a devastating impact on a developing economy because it affects mostly young and middle-aged adults in their most productive years (Rosen *et al.,* 2003; Barnette and Blaikie, 1992). HIV remains a burden to a work environment when an infected person is consistently absent from work (Poudel, Newlands & Simkhada, 2017). A study among Nepalese found that there is a cost in low production that affects organisations when an infected employee is unable to work or be present at work because of poor health and, as a result, reduces its productivity and efficiency (Poudel, Newlands & Simkhada, 2017).

The impact of HIV in the workplace can be viewed from the employers' and the employees' perspective: although their perspectives sometimes overlap, they may diverge in other ways (Rosen *et al.,* 2003). The employers' and employees' perspectives are largely based on their needs. The needs of the employers may include keeping the costs of insurance, recruitment and the cost of absenteeism low, and keeping productivity high. While the needs of the employees may cover a financial cost of treatment, taking regular time off work and flexible

work patterns. HIV not only drives up health care costs and benefit payments but also affects productivity for years (Rosen *et al.,* 2003). The absence of an employee not only affects the organisational management but can also increase workload, working hours and affect working relationships with other colleagues (Buck *et al.,* 2011). In an organisation where no colleagues can cover for the sick person, the person may eventually not take time off and that, in the long-term, may have an impact on the work productivity and wellbeing (Buck e*t al.*, 2011). The HIV epidemic has led to increased labour costs and slow growth rates in many developing economies (Rosen *et al.,* 2003). AIDS has forced employers to spend more time coping with low productivity in their organisations whilst also addressing the challenging legal, social, and political concerns that stem from the epidemic (Rosen *et al.,* 2003).

Employers in many developing countries face considerable pressure from governments and non-governmental organisations to spend more funds on tackling HIV/AIDS and to provide jobs and more funds for the families of those infected (Rosen *et al.,* 2003). As HIV has a great impact on productivity and individuals' lives, employers may have to work together with people living with HIV/AIDS (PLWHA) to improve their experience of HIV management while living with HIV infection. Addressing HIV in the workplace by supporting employees living with HIV/AIDS will lead to fewer economic and healthcare burdens, independent financial responsibilities and increased productivity (Healthy Working Lives, 2013). Developed countries may not be burdened with HIV as much as low or middle-income countries because of public awareness and less prominent stigmatising behaviours towards people with HIV/AIDS. Today, in many parts of Africa, HIV-related stigma is a concern (Lever and Wainberg, 2015).

1.3 Stigma

Goffman, (1963) believes that we, as humans, have a 'self'- what we perceive our 'self' to be, as a result of interacting with our society. We also seek to understand what others think about us. The greater sense of 'self' is what we think others think about us.

According to Goffman, social stigma can be defined as

> '*an attribute that is deeply discrediting… a stigmatised person is limited from a whole and known person to a tainted discounted person'* (Goffman, 1963, p.3).

Goffman reported stigma in two ways: (i) the discreditable and the discredited and (ii) universal or historical stigma. A *discreditable* person is yet to reveal his HIV status and has been able to conceal it so that no one has yet found out. It could however be revealed by others unintentionally or accidentally. There is also a possibility that no one would find out about the HIV positive status and the infected person hopes that no one finds out. However, the *discredited* people have had their status disclosed to others either by themselves or by someone else. In this case, HIV infection cannot be concealed due to visible HIV symptoms and as such, the HIV-infected people take the decision to disclose their HIV-positive status to others.

The second type of stigma reported by Goffman is called *universal or historical stigma* which can be understood in two ways; *the external deformity* and *tribal stigma*. The overt or external deformity explains deviations in personal traits where a person is seen to be weak, dishonest or may be deviant because of being unemployed, homeless or addicted to drugs. Falk (2001) called this type of stigma an *achieved stigma*. It explains stigma as a means whereby people are categorized as outsiders due to their actions. For instance, a criminal can be seen as an outsider because of the crime committed. The *tribal stigma* happens not necessarily because of what an individual has done but their affiliation with a particular ethnic group such as being an African American or Jewish. Falk (2001) called this type of stigma an *Existential stigma*.

Using Goffman's (1963) explanation on stigma, six dimensions of stigma that conform with the discreditable and discredited stigma will be explored to understand the role of the stigmatised and the offender. Stigma can be *concealed* - this explains to what extent an infected person can conceal its HIV positive status; *a course of the mark*- where over time, the disease may progress to a worse state – AIDS; *disruptive* – when HIV gets in the way of normal daily

activities of an individual and becomes visible to others; *aesthetics*- the level at which others react to HIV which dictates how people conceal their stigmatised status; o*riginated* - where others think people with HIV/AIDS are infected accidentally or because of immorality which then defines the level of support to be received from the society. This is also related to the type of stigma explained by Falk (2001) which is based on what a stigmatised person has done or was responsible for doing called an *Achieved* stigma, and finally, *periled* - the serious danger of HIV/AIDS to others, or whether others believe that an infected individual can be accommodated in the society.

While other dimensions of stigma explain the disastrous segregation faced by people living with HIV/AIDS, the *peril* dimension of stigma explains the experience of an employee living with HIV/AIDS where some employers believed that employing an HIV-infected person could be dangerous to other employees. This is because some employers undermine the ability of an HIV-infected person to perform the required task in the workplace because of fear of consistent ill-health and absenteeism.

A stigmatised group is marked as inferior in the society and for these ideas to thrive, stereotypes and/or generalisations, whether accurate or not, must be accepted and maintained by a substantial number of people in the society (Monjok, Smesny & Essien, 2009). As the stereotypes become sustained by a society, the affected group or people are stigmatised. Stigma can come in different forms as earlier mentioned (Heidi, 2013). Stigma also follows the process of categorisation (details of categorisation of groups are found in 2.8.1.1 of this thesis); and as a consequence of stigma; the affected people are categorised in a group (Lynch and Rodell, 2018; Worchel *et al.,* 1998). When such categorisation is formed, the society starts to treat such people differently. The stigmatised group is then faced with frustrations and acts irrationally. The irrational behaviour becomes a proof for justifying the placement of the group in this category.

According to studies on stigma (Weiner, Perry & Magnusson, 1988; Falk, 2001; Heidi, 2013), once stigma is enacted and becomes visible, it's mostly irreversible. Although, it could be argued that the stigmatised people may change their social settings to conceal their stigmatized status, as soon as it becomes visible in their new social settings, they regain their lives as categorised inferior individuals. This also explains people living with HIV/AIDS who may have once experienced stigma, then moved to a new environment mainly to conceal their HIV positive status. However, the stigmatisation may continue if their status is known to an individual or a group who may potentially stigmatise them.

The stigmatisation of people living with HIV has been the focus of academic researchers owing to its impact on infected persons and members of family, friends and the community at large (Dean, 2014). The negative public perception towards people living with HIV could make an individual be less likely to seek early testing or treatment and management of diseases (Dean, 2014; Odimegwu, Adedini & Ononokpono, 2013; Senyalo, Maja & Ramukumba, 2015). Furthermore, one of the most important challenges is the common social views on the mode of transmission of HIV (NPHA, 2009). For instance, studies conducted in South Africa and Ghana revealed people's view of HIV transmission. It was reported that HIV could be transmitted through mosquito bites or sitting next to/ touching an infected person (Tenkorang, 2013; Bogart *et al.,* 2011). These views were particularly reported in many parts of sub-Saharan Africa where HIV is seen as a death sentence or could be cured by eating fresh vegetables or sleeping with a virgin (Senyalo, Maja & Ramukumba, 2015; Ross, Essien, & Torres, 2006; Sano *et al.,* 2016). These views have shown the misconception of the treatment of HIV/AIDS and how people diagnosed with HIV/AIDS sought for other means to get cured. The misconception that HIV is a death sentence has continued to impact on how open people infected with the disease could be about their HIV status without being stigmatised. According to Heidi (2013), social stigma is a negative response to a person or a group of people with different characteristics to that of the social dominant norms. The dominant norm could be what is acceptable by the large majority of people in a society. The characteristics that might

negate the societal norm could stem from physical and personality traits, and some ideologies. The physical attributes include people with physical traits such as hunchback, dwarf, visible birthmarks; personality traits such as men with high voice; people that are considered deviant because of their actions such as criminals, prisoners; people excluded as minorities; and people that are stigmatized because of their illness such as HIV/AIDS or mental illness.

The social views may better explain the low adherence to HIV treatment and the social stigma associated with high prevalence of HIV/AIDS infection in sub-Saharan Africa. The United Nation for AIDS (2017) targets 2020 to work towards an achievement where 90% of the people living with HIV/AIDS will know their status, 90% will have access to HIV treatment, and 90% will have viral suppression. Having easy access to HIV treatment could discourage the aforementioned views, especially in many parts of sub-Saharan Africa where these views are still widely held.

The workplace is an institution where wider social behaviours such as stigmatisation exist (Breuer, 2005). Across various literature (Jans, Kaye and Jones, 2012; Henderson, et al. 2012; Saal, Martinez & Smith, 2014), people's conditions are perceived in two ways; these include visible conditions and invisible conditions. Visible characteristics of people 's identities are defined as 'the traits that can be observed by seeing or speaking with someone, whereas the invisible identity cannot be discerned' (Sage and Joseph, 2015). An invisible condition becomes known or is apparent when an individual discloses to others (Saal, Martinez & Smith, 2014). People who disclose their invisible conditions are stigmatised because they are perceived to be capable of performing their duties in the workplace which a visibly disabled person is understood as possibly unable to do, but, in reality, they may not be capable of meeting their employer's expectations (Hermanns, 2013). There is evidence (Dean, 2014; Odimegwu, Adedini & Ononokpono, 2013; Senyalo, Maja & Ramukumba, 2015) that people with infectious diseases, and especially HIV/AIDS, are being stigmatised. Stigmatisation or the fear of being stigmatised, can affect the ways or whether the affected person would disclose their disease to their social and professional networks. Stigmatisation can be

distressing for people with an invisible condition such as HIV as they may be seen as lazy by others.

1.3.1 Courtesy stigma

Courtesy stigma, also known as 'stigma by association' involves public disapproval as a result of associating with someone or a group having a stigmatised condition or trait (Phillips et al., 2012; Sigelman et al. 1999; Birenbaum, 1970). Stigma is also linked to labeling, stereotyping, categorizing, status loss and discrimination. Studies (Rao et al., 2008; Senyalo, Maja & Ramukumba, 2015) have investigated stigma that affected those who experienced stigma directly. In Nigeria, evidence (Odimegwu, Adedini & Ononokpono, 2013) has shown the impact of stigma on the rate at which PLWHA attend counselling and treatment. A considerable number of people still have a negative perception about people living with HIV/AIDS and as a result, less people access voluntary counselling and treatment in Nigeria. However, stigma goes beyond the affected individual: it is extended to people who are closely associated with the stigmatised individual or group who come in contact with a stigmatised person. In addition, studies (Hamlington et al., 2015; Birenbaum, 1970) have reported on the impact of courtesy stigma on the victim's family, and particularly those who support the infected or stigmatised individuals.

As previously stated in section 1.2.1 of this thesis, caring for people with stigmatised conditions such as HIV/AIDS can be demanding. It could also attract consequences such as blame, social isolation, financial difficulties and stigma (Mugisha *et al.,* 2013; Phillips et al., 2012; Chandran *et al.,* 2016; Lunberg *et al.,* 2016; Birenbaum, 1970). The stigma extended to caregivers (courtesy stigma) limits disclosure of the stigmatised condition. Birenbaum (1970) reported the impact of courtesy stigma on mothers who care for disabled children who often depend on specialised and diagnostic facilities for their day-to-day activities. In the case of people living with HIV/AIDS, people closely related to an infected person are more likely to be stigmatised, hence, such people develop a strategy such as limiting or controlling information to avoid courtesy stigma (Macrae, 1999). The strategy is targeted at preserving the public face

of the family and that of its member. Similarly, Parfene, Stewart & King (2009) investigated employees who had children with epilepsy compared to other conditions like asthma. It was found that employees who had children with epilepsy take time off work regularly to care for their children but as a consequence, they received greater workplace penalties and fewer workplace rewards. This shows the impact of caring for people living with stigmatised conditions.

Furthermore, employers were reported to face courtesy stigma. In fact, courtesy stigma is said to be one of the reasons why employers are reluctant to recruit people living with HIV/AIDS. For instance, studies (Liu *et al*., 2012; Tracey and Phillips, 2016; Rao *et al*., 2008) reported the low rate of recruiting PLWHA due to concerns about the organisation's reputation. For employers, recruiting people living with HIV may affect the public image of the company, drive away customers and also make other colleagues feel uncomfortable working with employees living with HIV/AIDS. As a result, they lose their job, which further aggravates the symptoms of their illness. It also means when they are without jobs, they are unlikely to meet their basic needs (Rao *et al*., 2008). The attitude of employers towards hiring HIV-positive persons has been reported to be highly negative and has also been linked to fear of transmission, and an inability to be competent enough to do the job (Liu *et al*., 2012). As a result, it could affect unemployment rates among PLWHA.

The UNAIDS Gap report (2014, p. 1) highlighted that 'people living with HIV/AIDS experience unemployment three times more than the national unemployment rate'. In addition, Groß, e*t al*. (2016) and Annequin, *et al*. (2016) found that the risk of unemployment is at the highest shortly after a person is diagnosed. This risk can be associated with some socio-economic factors such as age, gender, education, the severity of the illness and frailty (Groß *at al*., 2016; Annequin *et al*., 2016). For instance, Groß, *at al*. (2016) reported that unemployment is common in women and younger patients, and this is linked to poorer education, frailty, and severity of the illness. Annequin, *et al*. (2015) concluded that the improvement in HIV care has not translated to an improvement in the rate of employment of PLWHA. A study (Legarth *et*

al., 2014) carried out in Denmark revealed that advancement in HIV treatment, HIV testing strategy, and public awareness has improved the rate of employment among PLWHA and reduced the disability rate. This implies that advancement in HIV treatment has contributed to more PLWHA entering or re-entering the workforce.

A study by (Wang *et al.,* 2014) investigated the impact of job loss on the physical and mental health of employees with chronic diseases in Northwest China and found that unemployment can be a stressful circumstance and can have a deleterious effect on a person's health. This is because it is easier for a 'healthy' person to find another job when one is lost than for someone with poor health (Wang *et al.,* 2014). Furthermore, poor health and opportunistic infections influence low rates of employment among people living with HIV (Conyers and Boomer, 2005). Opportunistic Infections (OIs) frequently occur among individuals with weakened immune systems, including people living with HIV/AIDS (Centres for Disease Control and Prevention (CDCP), 2015). The opportunity to return to work after diagnosis is increasing among PLWHA. However, an individual is left with a choice of concealing their invisible status or revealing it, and as such the decision is based on the necessity to disclose.

Stigmatisation can result in concealment of HIV positive status and denial of diagnosis which not only affect care and treatment but has a substantial implication for prevention (Senyalo, Maja & Ramukumba, 2015). Myths of HIV transmission coupled with societal prejudice contribute to the issues of stigma, discrimination, social exclusion, low self-esteem, accusations of infidelity, guilt and fear, and make HIV disclosure a critical and difficult issue to people living with HIV/AIDS (WHO, 2014a).

The word *Disclosure* was first investigated by Sidney Jourard in 1971 and was defined simply as 'telling others about the self'. Since then an extensive amount of information on disclosure has been produced leading to a significant change in the way we understand the phenomenon (Derlega *et al.,* 1993). Disclosure is an on-going social and psychological process of sharing critical health information with others (Mayfield *et al.,* 2008). However, a decision to disclose

critical health information gives a complex situation of who to disclose to and what sort of information should be disclosed (Hubach *et al.,* 2015). Breuer's (2005) research on disclosure in the workplace reported that this type of disclosure contains critical and complex decision making and involves proper planning due to an increase in the number of PLWHA wanting to return to work after diagnosis. Hence, disclosure could be needed when employees require workplace support from their employers in other to do their duties. A case study of a man with HIV who disclosed his status in the workplace showed that after disclosure, he felt that he had more support, less stress and experienced an improved relationship with most of his co-workers (McMahon, 2003). Meanwhile, there is an evidence that employers dismissed their employees after disclosing their HIV positive status due to the direct and indirect impact on their productivity or the company's expenditure (Conyers and Boomer, 2005; Rosen *et al*., 2003). A study (Lim and Loo, 2000) aimed at exploring opinions on recruiting PLWHA among employers and human resource managers showed negative reactions to disclosure of HIV status in the workplace and this reaction reflected the low rate of disclosure in the workplace (Conyers and Boomer, 2005).

1.4 Rationale for the study

HIV disclosure is a means by which people access support within both their social and professional networks. However, not much is known about HIV disclosure in the workplace among PLWHA in Nigeria, and the only relevant peer-reviewed study (Arinze-Onyia, Modebe & Aguwa, 2015) for this setting comes from a descriptive quantitative cross-sectional study that uses questionnaire to collect data from patients who are employed and receiving treatment from one of the hospitals in Nigeria. The wider literature (outside Nigeria and the African continent) suggests that HIV disclosure has been reported as a potential means of adhering to treatment and care and accessing healthcare support (Li *et al.*, 2015). It has also been recommended by healthcare professionals during counselling to encourage safer sex in most parts of sub-Saharan African countries (Amoran, 2012; Muhimbuura *et al.,* 2014).

In 2013, the national policy in Nigeria encouraged confidentiality of all employee data in the workplace and the choice to disclose one's HIV status or not (Federal Ministry of Labour and Productivity (FMLP), 2013). Since 2015, the law prosecutes anyone who exposes others to the virus without disclosure of their status (Bernard, 2015). Given the unclear stance of the Nigerian government on the rights of PLWHA to disclose their HIV positive status or not, especially to their employers, there is a worrying lack of any regulatory framework around the employee's right of disclosure in the workplace. In relation to HIV disclosure in the workplace, employers may feel reluctant to employ PLWHA, stating serious concerns about the costs (direct and indirect) of employing an HIV positive person. This has been evidenced in similar studies (Rosen *et al*., 2003; UNAIDS, 2000). This evidence in addition to the limited empirical data on HIV disclosure in the workplace in Nigeria makes it difficult to understand the employees living with HIV/AIDS and their perceptions of HIV disclosure in the workplace and how this impact on their life and work.

This thesis explores HIV disclosure by collecting and synthesising the evidence available on HIV disclosure among PLWHA in Nigeria via a systematic review of the literature and by adding to the current understanding of HIV disclosure in the workplace via face-to-face interviews with PLWHA. A synthesis of evidence from the systematic review of the literature with the qualitative findings of the interviews with PLWHA is presented in chapter three and four of this thesis. This study makes a contribution to the understanding of factors that influence disclosure or not in the workplace of PLWHA, and the impact of disclosure or non-disclosure of HIV/AIDS in the workplace.

1.5 Aims and objectives

The overall aim of this study is to explore HIV/AIDS disclosure in the workplace among people living with HIV/AIDS in Nigeria.

The main objectives of this study are to:

1. Collect and synthesise research-based evidence on HIV/AIDS disclosure in Nigeria;

2. Explore the factors that influence people living with HIV/AIDS in Nigeria to disclose their HIV status or not in their workplace;
3. Understand to whom those living with HIV/AIDS disclose in their workplace, and why;
4. Understand the psychosocial impact and practical implications of disclosure in the workplace for people living with HIV/AIDS.

1.6 Research design & methodology

Substantial evidence (Fesko, 2001; Liu *et al*., 2012; Tracey and Phillips, 2016) has been reported on attitudes towards PLWHA in the workplace. However, very little qualitative research has investigated the perception of HIV disclosure at work (Obermeyer, Baijal & Pegurri, 2011). Therefore, this study is designed to explore HIV disclosure in the workplace. The study involved two methods: a systematic review of the literature and qualitative interviews.

The systematic review method collects and synthesises evidence from the existing literature on HIV/AIDS disclosure in Nigeria. Meta-analysis was carried out to synthesise the results of the included articles. Also, a checklist developed by the Cochrane Review for mixed methods studies was used to assess the quality of included studies, and to draw conclusions. The systematic review identified evidence gaps in HIV disclosure in the workplace in Nigeria.

The primary study was designed to address the gap on HIV disclosure in the workplace among people living with HIV/AIDS in Nigeria using a semi-structured interview schedule as the main research tool.

1.7 Potential impacts and contributions

This study contributes to the understanding of factors that influence disclosure or not in the workplace of people living with HIV/AIDS, and the impact of disclosure or non-disclosure of HIV/AIDS in the workplace. This study makes a contribution to knowledge and offers the potential to support advocacy and inform policy making. The advocacy is channelled towards better policy-making and implementation in the support of employees living with HIV/AIDS,

and protection against any form of discrimination or stigma in the workplace. It could also inform policies for healthcare professionals to provide advice or to counsel employed PLWHA on workplace disclosure.

1.8 Scope of the thesis

This thesis has 6 chapters. A brief summary is provided for each chapter as follows.

Chapter 2: Literature review. It presents a brief history of AIDS and explores the social and biomedical approach to the HIV epidemic. It also discusses the prevalence of HIV globally, regionally (African) and nationally (Nigeria). A critical presentation of the literature on disclosure of critical condition (HIV) and possible factors that influence the disclosure of HIV/AIDS is provided. Finally, it explains the theoretical framework, employee decision-making and reviews other theories related to this study.

Chapter 3: Methodology. It explores the philosophical stance of the study. It then reiterates the aims and objectives of this thesis as presented in this chapter (Chapter 1). This study is in two phases using two methodological approaches: the systematic review approach and qualitative approach (semi-structured interview). *Phase one* is called the systematic review methodology. It begins with a reminder of the study objective that the systematic review aims to address, and outlines the systematic review aims and objectives. The methods are then presented in sections including research design, search and screening strategy, and data extraction and analysis. *Phase two* is the qualitative primary methodology. It presents the methods used in the qualitative study and outlines the theoretical perspectives of the research that underpins the qualitative study and presents the research design. The eligibility criteria for the study are discussed, and then the recruitment procedures used for both the hospital and the patients are presented. The chapter finishes by presenting the pilot study that was carried out prior to the main study, along with the necessary adjustments required to the interview schedule.

Chapter 4: Findings. It is in two phases: the systematic review findings and the qualitative study findings. Phase one begins with the breakdown of the studies included in the review and then outlines the characteristics of the studies. Meta-analysis was used to measure the effect of the rate of disclosure and the supportive reaction of the recipient. Methodological issues are discussed by carrying out a quality appraisal of each study included in the review based on their study design, the sampling strategy, the sampling size, the eligibility criteria, ethical procedures, and the findings. Finally, the results of the systematic review are summarised, followed by the limitations of the review and suggestions for future research are presented. Phase two outlines the findings of the qualitative study from the semi-structured interviews which were held with patients accessing HIV treatment in the hospital. This begins with the demographic information of the participants, followed by an overview of the main themes. The main themes are discussed in more detail and supported by the use of direct quotations. Finally, the summary of the findings is presented.

Chapter 5: Discussion. It brings together the findings of both the systematic review and the qualitative study and discusses these within the wider literature of HIV and disclosure in the workplace. This chapter then presents the findings within the theoretical model that was adopted.

Chapter 6: Conclusion. It emphasises the contributions of this study research to policies and practice such as its likely impact on government, organisations, the public, and people living with HIV/AIDS. The chapter ends with the strengths and limitations of the thesis

1.9 Summary

This chapter introduces HIV/AIDS, providing information about its global epidemic and its effect on a nation's economic, social and political spectrum. It reports the HIV burden on the infected individual, affected family members, friends, the workplace and the community. Finally, it introduces the aims and objectives and the scope of this thesis.

The next chapter provides a comprehensive review of the current existing literature on HIV and disclosure in the workplace.

Chapter Two: Literature review

2.0 Introduction

This chapter presents the aetiology and epidemiology of HIV/AIDS globally, regionally and in Nigeria as one of the countries with a high prevalence of HIV. It further explores the burden of HIV on an individual, families, caregivers, and the workplace. Finally, it discusses HIV disclosure, specifically the implications of HIV disclosure in the workplace.

2.1 Aetiology and Epidemiology of HIV/AIDS

About four decades ago, most people knew nothing about HIV/AIDS due to lack of information about the condition, but recently, the vast majority of people around the globe have heard about it (Stolley and Glass, 2009). The Centre for Disease Control (CDC) in Atlanta, Georgia received the first report of men infected with a form of Pneumocystis Carinii Pneumonia (PCP) in 1981 together with a report on a form of a skin tumour called Kaposi's Sarcoma (KS). The two infections were rare and could only be found among people with a weak immune system such as the elderly and other immunosuppressed individuals. However, during this time, it was found mostly among young gay men (Aggleton and Homans, 1988; Stolley and Glass, 2009). Many of these people died, some experienced persistent swollen lymph nodes and others remained healthy for months and years after being diagnosed (Stolley and Glass, 2009).

AIDS was still an unknown entity not only to the wider population but also to most healthcare professionals. In early 1980's in New York, the first cases of PCP were diagnosed among heterosexual intravenous drug users. In 1982, CDC coined the term AIDS as Acquired Immunodeficiency Syndrome. The causal effect was first linked to a single agent; then attention was shifted to behavioural lifestyle. Some believed that HIV infection had long existed over two decades ago in the Democratic Republic of Congo (previously known as Zaire) before its discovery in America and was found in the blood of a man in Kinshasa (Stolley and Glass, 2009). The medical researchers presented HIV as incurable and that once an individual contracted HIV, treatment was only the means to sustain an individual for a much longer time (Stolley and Glass, 2009).

Aggleton and Homans (1988) reported that the more unsafe sex an individual engaged in, the greater the risk of infection. In fact, some of the conservative religious leaders believed that it was a punishment from God as a result of accepting homosexuality in the society; AIDS was initially linked to sexuality as gay men were seen to be more at risk (Stolley and Glass, 2009). However, AIDS affected people from all sexual orientations, gender, race, age and social groups (Aggleton and Homans, 1988). Today, most people with a positive HIV status are

heterosexual as sexual activities or orientation are not the main way of getting HIV infected (UNAIDS, 2016). Evidence shows (Awofala and Ogundele, 2016) that other ways such as unsafe blood transfusion, less likelihood of condom use, conflicting and mixed messages around abstinence and condom promotion, lack of sex education in schools, unhygienic dental practice and substance abuse, were identified as common transmission routes.

2.1.1 HIV and its progression to AIDS

According to Stolley and Glass (2009), the terms 'HIV' and 'AIDS' are often used interchangeably. HIV is a virus that may cause AIDS. A person infected with HIV is said to be HIV positive (HIV+). A person that is HIV+ may not show any symptoms of infection (asymptomatic), as many live for decades. This is the result of the immune system being able to control the virus (Stolley and Glass, 2009). Hence, being HIV+ does not mean an individual will develop AIDS (Stolley and Glass, 2009).

As HIV progresses, it makes the immune system weaker and susceptible to infections, resulting in the advanced stage of HIV (between 2-15 years) that results in infected persons developing Acquired Immune Deficiency Syndrome or 'AIDS' (WHO, 2014b). HIV progression to AIDS varies with persons according to the varying time it takes for an individual to be infected with HIV (Stolley and Glass, 2009). AIDS is commonly referred to as a modern epidemic: it is not just an epidemic in a particular country or continent, it is a disease found globally (Stolley and Glass, 2009).

2.2. Epidemiology of the disease

2.2.1 Global prevalence

Since 1996, the use of antiretroviral therapy (ART) has changed HIV from being a fatal disease to a chronic disease (McDonald *et al*., 2016). This means that people started living longer than when there was little or no provision for ART. In 2014, more than 36 million people were living with HIV. In March 2015, there was an increase of 15 million in the number of PLWHA accessing ART from approximately 14 million in 2014 (UNAIDS, 2016). The new infections

have reduced by 35% since the year 2000 with annual new HIV infections declining at a rate of 1.8 million compared to about 2.2 million people in 2014 and 3.3 million people in 2000 (UNAIDS, 2016).

The increase in adults receiving treatment moved from 23% in 2010 to 41% in 2014. Also, the number of children accessing treatment increased from 14 % to 32% between 2010 and 2014 (UNAIDS, 2016). The aim of the global response agencies was to target pregnant women having an HIV infection to stop transmitting it to their unborn children. Hence, there was a rise of about 73% in the number of pregnant women accessing treatment; which caused a sharp decrease in the number of children newly infected by 58% (UNAIDS, 2016). With the increased access to treatment, AIDS-related deaths reduced by more than 42% in 2004 (UNAIDS, 2016). Approximately 1.2 million people died of AIDS-related death in 2014, which it is estimated around 2 million if the treatment accessibility had been limited (UNAIDS, 2016). Table 1 shows the prevalence rate of PLWHA by different regions.

Table 1: The prevalence of People Living with HIV by Region

Regions	Estimated number of people (all ages) living with HIV
Asia and the Pacific	5,100,000
East and Southern Africa	19,000,000
Eastern Europe and Central Asia	1,500,000
Latin America and the Caribbean	2,000,000
The Middle East and North Africa	230,000
West and Central Africa	6,500,000

Western & Central Europe and North America	2,400,000
Global Total	36,700,000

Source: 'Global Health Observatory data repository' (WHO, 2017)

Table 1 above shows that the East and Southern Africa regions that are located within sub-Saharan Africa has the highest prevalence of HIV.

2.2.2 AIDS in Sub-Saharan Africa

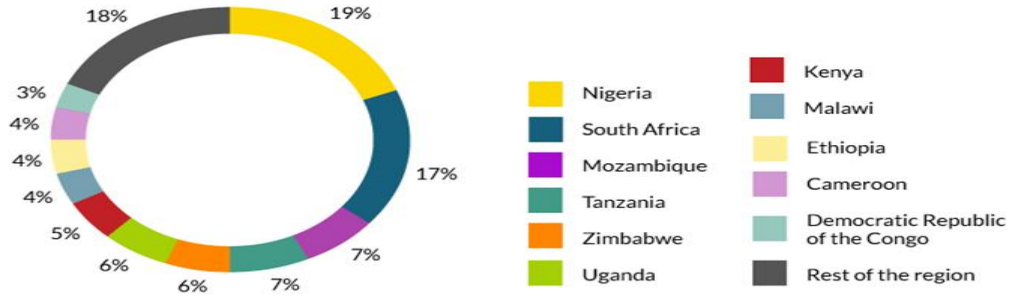
In the early year of 1986, AIDS epidemics became apparent, with increasing numbers of cases reported to WHO (Barnette and Blaikie, 1992). HIV is a concern for global, regional and national health (WHO, 2015). Compared to the developed countries, sub-Saharan Africa is still the most affected region with the highest rate of HIV infection (UNAIDS, 2015). Approximately 75 % of PLWHA are in Africa. However, Africa has just over 10% of the overall world's population (Nasidi and Harry, 2006). Due to differences in the nations' political, social and economic levels, different countries show different prevalence rates. In East and South Africa, it rates as one of the highest in the world with Botswana and Swaziland having a prevalence rate of over 35%. However, the rate has become lower in West Africa with countries having below a 10% rate (Nasidi and Harry, 2006). Children are, however, more affected either through transmission between mother and child or loss of their parent(s) to AIDS. Heterosexual transmission with unsafe sex practices accounts for almost 80 % of HIV transmission in Africa (Nasidi and Harry, 2006).

AIDS has also been labeled as 'an African disease' that labels a Black community as a victim (Barnette and Blaikie, 1992; Stolley and Glass, 2009). Barnett and Blaikie (1992) further reported that HIV infection is not restricted to, or associated with, a particular race, ethnic group or sexual orientation as this will reflect a cultural and social prejudice that could contribute to stigmatisation. Social and cultural issues, such as poverty, limited access to food and health services, less social welfare and inequality between the rich and the poor within a

community, family or household structure have contributed to the HIV epidemic (Barnette and Blaikie, 1992).

In 2013, people living with HIV in sub-Saharan Africa were estimated at 24.7 million, new infection was estimated at 1.5 million, and 1.1 million deaths from AIDS-related illnesses were recorded. Figure 1 below shows the variations in AIDS-related deaths among the most affected countries in sub-Saharan Africa in 2013. The severity of HIV transmission and its impact on mortality and morbidity mean AIDS remains the leading cause of death in Nigeria (Nasidi and Harry, 2006). Hence Nigeria, as part of sub-Saharan Africa, continues to bear a disproportionate share of the global burden of HIV.

Figure 1: AIDS-related deaths in Sub-Saharan Africa, 2013



Source: HIV and AIDS in sub-Saharan Africa Regional Overview (Averting HIV and AIDS) (AHA), 2016.

The above Figure 1 shows AIDS-related deaths within countries of sub-Saharan Africa. It identifies that almost one fifth of AIDS-related deaths were found in Nigeria followed by South-Africa and Mozambique with 17 % and 7% respectively. Also, about 9% of the global population of people living with HIV/AIDS live in Nigeria.

2.2.3 AIDS in Nigeria

This section explores the history of HIV, the epidemiological account including the geographical distribution and prevalence across Nigeria.

2.2.3.1 History of HIV in Nigeria

According to Awofala and Ogundele (2016), two cases of AIDS were diagnosed in 1985 and reported in 1986 in Lagos state, south-western Nigeria. The infected persons were two female sex workers from other West African countries. The news of the first cases of HIV infection sent fear, doubt and disbelief to the nation as it was perceived as a disease sent from America to discourage sex, with one meaning of AIDS that emerged being '**A**merican **I**dea for **D**iscouraging **S**ex' (Awofala and Ogundele, 2016). A further research by Awofala and Ogundele (2018) reported that most affected were adults over the age of 15 years while HIV-infected children had a substantial increase in 2014 (Awofala and Ogundele, 2018). Presently, the most-at-risk constitutes sex workers, men who have sex with men and drug users who use contaminated injections.

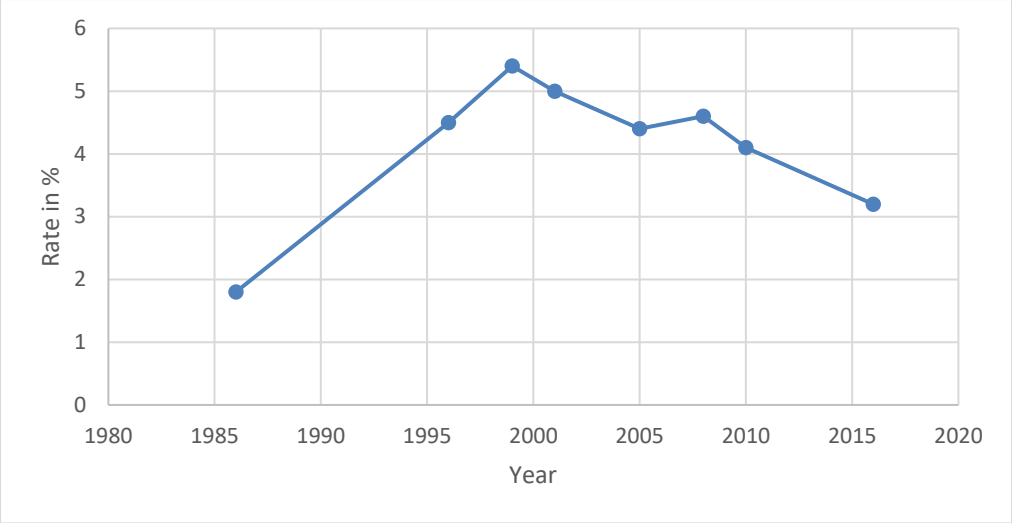
Nigeria has 36 states and the Federal Capital Territory (FCT), Abuja (Bashorun et al., 2014). Geographically, seven states were mostly affected with over 8% prevalence rate. They are Gombe, Plateau, Benue, Nasarawa, Cross Rivers, Akwa-Ibom and the FCT where Benue had the highest number of HIV-infected people of 13.5%. The least affected states include Ekiti, Kebbi, Katsina, Jigawa and Bauchi states where Kebbi, Ekiti and Jigawa had the lowest prevalence rate below 2.0% (Bashorun et al., 2014; Global AIDS Response Country Progress Report, 2015).

As HIV remains a concern in Nigeria, some laws and policies have been put in place to guide response to HIV/AIDS (Global AIDS Response Country Progress Report, 2015). These policies include the national policy on HIV/AIDS that was implemented in 2009 to guide relevant agencies to ensure the prevention of the rise of HIV incidence and to make treatment, care and support available to those that are infected or affected. Other regulations include the right of every Nigerian to exercise their fundamental human right to life without any form of discrimination.

2.2.3.2 Epidemiology of HIV

Compared to other sub-Saharan African countries, the HIV/AIDS epidemic is at a lower level (AHA, 2016). Nigeria has the second highest HIV prevalence in sub-Saharan Africa (Nasidi and Harry, 2006; Arinze-Onyia, Modebe & Aguwa, 2015). Nigeria also has the third-highest prevalence in the world after India and South Africa (Awofala and Ogundele, 2016). The prevalence rate of HIV in Nigeria (See figure 2) in 1986 was 1.8%, increasing to 4.5% in 1996 and to 5.4% in 1999 with the most prevalent age group consisting of young people at their working age (Nasidi and Harry, 2006; Arinze-Onyia, Modebe & Aguwa, 2015), while in 2001, the prevalence rate dropped to 5.0%, 4.4% in 2005, 4.6% in 2008 and 4.1% in 2010 (National Agency for the Control of AIDS (NACA), 2015). In 2016, the prevalence rate was about 3.2%, which was 0.9% lower compared to 2010. The current prevalence shows that new infection is at its lowest level compared to previous years. Notwithstanding this, PLWHA are still more than 3 million and more than 200,000 new HIV infections, and about 160,000 AIDS-related deaths were recorded in 2016.

Figure 2: The prevalence rate of HIV in Nigeria



The data collected from the Nigeria's surveillance system, which is the most comprehensive data on HIV/AIDS in Nigeria, contained data regularly collected from different regions, states, cities, towns and villages in the country (Bashorun et al., 2014). The data mostly targeted pregnant women aged between 15 and 49 years registered under the antenatal care programme across various hospitals/maternity clinics in the country (Federal Ministry of Health, 2014). The epidemiological assessment was not available to give up-to-date information on the incidence and the prevalence of newly infected patients due to a weak monitoring and evaluation system connecting the activities of the state and local HIV records with the national record of the population of people living with HIV/AIDS (Awofala and Ogundele, 2018). The lack of a central data system that harmonises HIV data of all levels contributed to the lack of sufficient information on the distribution of HIV prevalence by regions in Nigeria.

Culture and religious beliefs along with social norms play an important role in how people understand HIV in Nigeria. As aforementioned, AIDS was believed to be an American disease that was transmitted to Africans to discourage sex. The belief may have contributed to the misconception of HIV. For cultural and religious reasons, sex is seen as a private subject in Nigeria as in many other African countries: discussing sex with young people, particularly girls was not considered culturally acceptable (Awofala and Ogundele, 2016). It is perceived that

girls are less able to make right choices with regards to sex until adult age. Young people have the highest prevalence of HIV/AIDS; this is due to restricted sex education and awareness leading to risky sexual behaviours (Awofala and Ogundele, 2016). Cultural and religious beliefs, misconception about HIV transmission and lack of sex education all contribute to the burden of the disease on the individual, community and organisations as will be discussed below.

2.3 Burden of the disease

Research has been conducted on ways we understand AIDS, its economic cost and how media have created a negative perception of AIDS. AIDS has also been associated with discrimination, racism, sexuality, and inequality (Aggleton and Homans, 1988). It has an effect, both directly and indirectly, on many people; the effect cuts across many social groups and divides people from one another (Stolley and Glass, 2009). The burden of the disease affects an infected individual, family members, friends, their communities and even has an effect in their workplace.

2.3.1 Burden on the infected individual

In addition to the overall impact on society, workplace, and careers, HIV/AIDS has a major impact on the individuals who are affected. The types of impact presented in the literature can be categorised into physical, psychological and socio-economic.

2.3.1.1 Physical impact

As soon as the virus enters a person's body, physical changes occur. This is mostly as a result of the body's immune system being compromised, and then opportunistic infections begin to invade the body, and the individual starts living with life-threatening conditions (Stolley and Glass, 2009). Physical or physiological symptoms come into play but vary among individuals with factors like age, overall health, and early diagnosis. Symptoms may not be visible enough to be noticed. However, after a few months of being infected, the majority may experience a flu-like sickness that may last for a few weeks, with symptoms like fever, chills, sore throat,

joint pain, swollen lymph glands, diarrhoea, headache, and muscle aches (Pietrangelo, 2004). The first stage experience called *acute infection* reproduces the virus rapidly as a result of having a large quantity of virus in the blood. The next stage, called the *clinical latent infection* stage, can last between 8 to 10 years or much longer depending on the individual, who may or may not have symptoms (Pietrangelo, 2004). As HIV advances, the CD4 count decreases more drastically with symptoms such as fatigue, shortness of breath, cough, weight loss, and diarrhoea. As it advances, it causes other infections and problems with eyes, lungs and digestive tract (Stolley and Glass, 2009; Pietrangelo, 2004). Health is about the mind and body (Freser & Greco, 2005): a physical illness such as HIV will also no doubt have some psychosocial impact as will be explained below.

2.3.1.2 Psychosocial Impact

The psychosocial impact of HIV on PLWHA cannot be underestimated. Because HIV is a life-threatening illness, an individual will react with fear of uncertainty, anger, blame, frustration, depression disorder and even withdrawal from their social groups (Peter, 2011). The fear experienced may arise as a result of perceived negative reactions from their environment associated with HIV/AIDS, the AIDS-related death of a spouse, divorce, loss of productive time or work hours due to frequent ill health which may eventually lead to unemployment. HIV affects all the areas of a person infected by HIV. People derive ways with which they cope with their illness in the face of stress and which reduce the impact of depression, withdrawal, and loneliness (Baltes and Baltes, 1990). As a result of the psychological impact, a coping mechanism is required. A coping mechanism theoretically predicts retention or maintenance of one's social role and control in life in the face of illness (Bowling, 2009). It is linked with the behaviour of an individual and that of his/her social group to deal with the situation (Barnette and Blaikie, 1992). For instance, an infected person might be able to cope with his/her illness through getting involved in activities such as attending support groups designed to meet other people with similar conditions so that the psychological impact of the illness will be limited.

HIV infection has been found to influence gender inequality, as women have a more devastating impact of HIV than men as will be discussed in the next section.

2.3.2 Gender inequality

Women face discrimination in many aspects worldwide, especially in literacy, violence and social power (Stolley and Glass, 2009). Inequality in these areas contributes to chances of having HIV or makes life challenging for women who take care of HIV patients (Stolley and Glass, 2009). According to the national HIV/AIDS survey conducted in 2013, the prevalence of female HIV infection is higher than male across all age groups except 35-39 and 40-44 years of age (Awofala and Ogundele, 2016; Arinze-Onyia, Modebe & Aguwa, 2015). Evidence shows that sub-Saharan Africa has 70% of the global total of new HIV infections with women constituting 58% of the affected people (UNAIDS, 2016).

The belief that poverty drives the epidemic of HIV has been long held (Parkhurst, 2010). For instance, female sex workers have the highest HIV infection in Nigeria (Nasidi and Harry, 2006). In a study conducted among countries in sub-Saharan Africa (Parkhurst, 2010) using national data that indicates HIV prevalence and socio-economic status, it was found that high rates of HIV infection among women is strongly associated with poverty. Furthermore, child marriage, low income, patriarchy, domestic violence, lack of formal education, and limited freedom of choice in sex and sexuality issues make women, especially the young people, more vulnerable to HIV infection (Nasidi and Harry, 2006; Awofala and Ogundele, 2016).

Many cultural and social practices violate women's human rights and increase the infection rate among women and girls (Nasidi and Harry, 2006). For instance, choice of marriage mostly depends on parents while many girls do not have the right to choose when and who to marry; this is mostly an acceptable norm in Northern Nigeria (Nasidi and Harry, 2006; Awofala and Ogundele, 2016). This may be due to cultural and religious beliefs. Young girls between 12 and 13 years of age are given away for marriage to adults who are old enough to be their fathers (Nasidi and Harry, 2006). For instance, in many countries, women are the main victims

of violence, such as rape, sexual assault, domestic violence, human trafficking, and female genital mutilation (Stolley and Glass, 2009). Also, women are less likely to be found in highly skilled positions as a result of their limited access to formal education (Stolley and Glass, 2009).

Nigeria traditionally is still a patriarchal society, such patriarchy often allows and gives more power to men to oversee the affairs of their homes while the major role of women is to take care of the home and raise the children (Nasidi and Harry, 2006). In some countries and cultures such as Northern Nigeria and some parts of south western Nigeria, men have the choice to have more than one sexual partner both within and outside marriage (Nasidi and Harry, 2006). Age, lack of education and low social status prevent women or girls from negotiating condom use to protect themselves against possible STDs (Nasidi and Harry, 2006; Parkhurst, 2010). High prevalence rates of women with HIV infection and millions of orphans have prompted more effort to revise the policy to address these concerns (NACA, 2015).

2.3.3 Legal framework and health policy

Since the emergence of HIV disclosure (in 1980s), there have been rights to disclose or not to disclose one's HIV positive status. However, criminalisation of people with HIV has been adopted by some countries where disclosure is a must when seeking a particular job or in some identified circumstance (Henry *et al*., 2015). Some countries around the world have made a strict rule on criminalising PLWHA if they fail to disclose their HIV positive status to their sexual partners before having any sexual activities. Henry, *et al*. (2015) argues that PLWHA should have the right to choose who to disclose to. However, the laws in various countries empower indirect, third party disclosure without the person's consent. Countries like the Democratic Republic of Congo and the Republic of Mali have increasingly used laws to limit the right of choice of disclosure. The Republic of Mali supports disclosure by doctors to partners if the infected individual fails to disclose after six months of diagnosis (Henry *et al.,* 2015). Canada, one of the countries that have a strict rule on criminalising PLWHA, criminalises non-disclosure of positive status due to the possibility of HIV transmission.

However, it excludes people that practice safer sex (e.g. the use of a condom) and having a low viral load (Patterson *et al.,* 2015).

Nigeria passed a similar law in 2015 but much stricter than the current legal framework in Canada. It does not have any defense relating to the risk of exposure, such as the type of sexual act, condom use, or use of treatment as prevention (Bernard, 2015). It also subjects anyone that transmits the virus to another person to at least 15 years imprisonment and could be increased to life imprisonment whether the person is aware of his/her positive status or not; this is categorised as sexual offences (HIV Justice Network, 2015). These sexual offences include indecent acts, incest, sexual harassment, sexual assault, and rape. Regardless of this, the Nigerian government, through the Federal Ministry of Labour and Productivity (FMLP), has focused on preventing HIV/AIDS by targeting the workplace across the country due to a substantial impact of stigma and discrimination both to the employers and to employees themselves (FMLP, 2013). However, there are still a number of challenges in implementing successful policies and programmes such as the rate of new infections among an economically active young population. In 2001, action has been taken to work with the International Labour Organisation (ILO) and other stakeholders to review the national workplace policies on HIV/AIDS by providing government, employers, employees and other stakeholders with the recommendation of the ILO concerning strategies to tackle HIV/AIDS in the workplace (ILO, 2001). Although this recommendation recognises the rights of all employees to privacy and the choice to disclose their status or not in the workplace (FMLP, 2013); Nigeria still criminalises PLWHA (Bernard, 2015).

There were arguments that criminalising PLWHA may affect access to healthcare specifically among women (Patterson *et al.,* 2015). The fear of disclosing personal and medical information may limit the access of care and reduces HIV voluntary testing. Public health advocacy and policymakers argue that criminalising HIV non-disclosure could have a negative impact on the health initiation programme designed for PLWHA (Patterson *et al*., 2015). Lack of trust in healthcare systems may affect ‘openness’ during the consultation, and fewer people

may agree to HIV testing and interventions. It is expected that after HIV diagnosis the person affected should be given appropriate care and referred appropriately to where treatment is given, and in the process of care, PLWHA expect medical confidentiality in the medical system (Patterson *et al*., 2015). Therefore, criminalising non-disclosure of HIV status could affect healthcare accessibility, criminalises more women and limits access to ART that reduces the viral load of PLWHA.

2.3.4 Socio-economic and financial impact

Socio-economic status (SES) is mostly measured as a combination of education, income, and occupation, or conceptualised as the social status or class of an individual or a group (American Psychological Association (APA), 2015). Disparities in socioeconomic status, including inequity in the distribution of wealth, income and access to services, affect everyone and are present in all societies (APA, 2015). HIV is a disease of social and economic inequality, as it mainly affects those of lower socioeconomic status and developing countries (Pascoe *et al*., 2015). When diagnosed with HIV, people with financial inability and instability may find it difficult to provide for their basic needs and care. A study conducted (Closson *et al.*, 2015) among sex workers revealed that a significant number of participants were engaged in sex work as an additional income due to limited job opportunities and economic vulnerability.

HIV reduces the financial ability of an infected person. An increased demand for medical care, frequent travel for hospital care, expensive ART, and a change in nutritional diets, all lead to increasing the household expenses. Financial inability may become more burdensome when both parents die of AIDS, and their children are faced with the financial burden. Socio-economic status and socio-cultural norms have put a substantial financial burden on women as a result of possible risk factors in the spread of HIV/AIDS (Awofala and Ogundele, 2016).

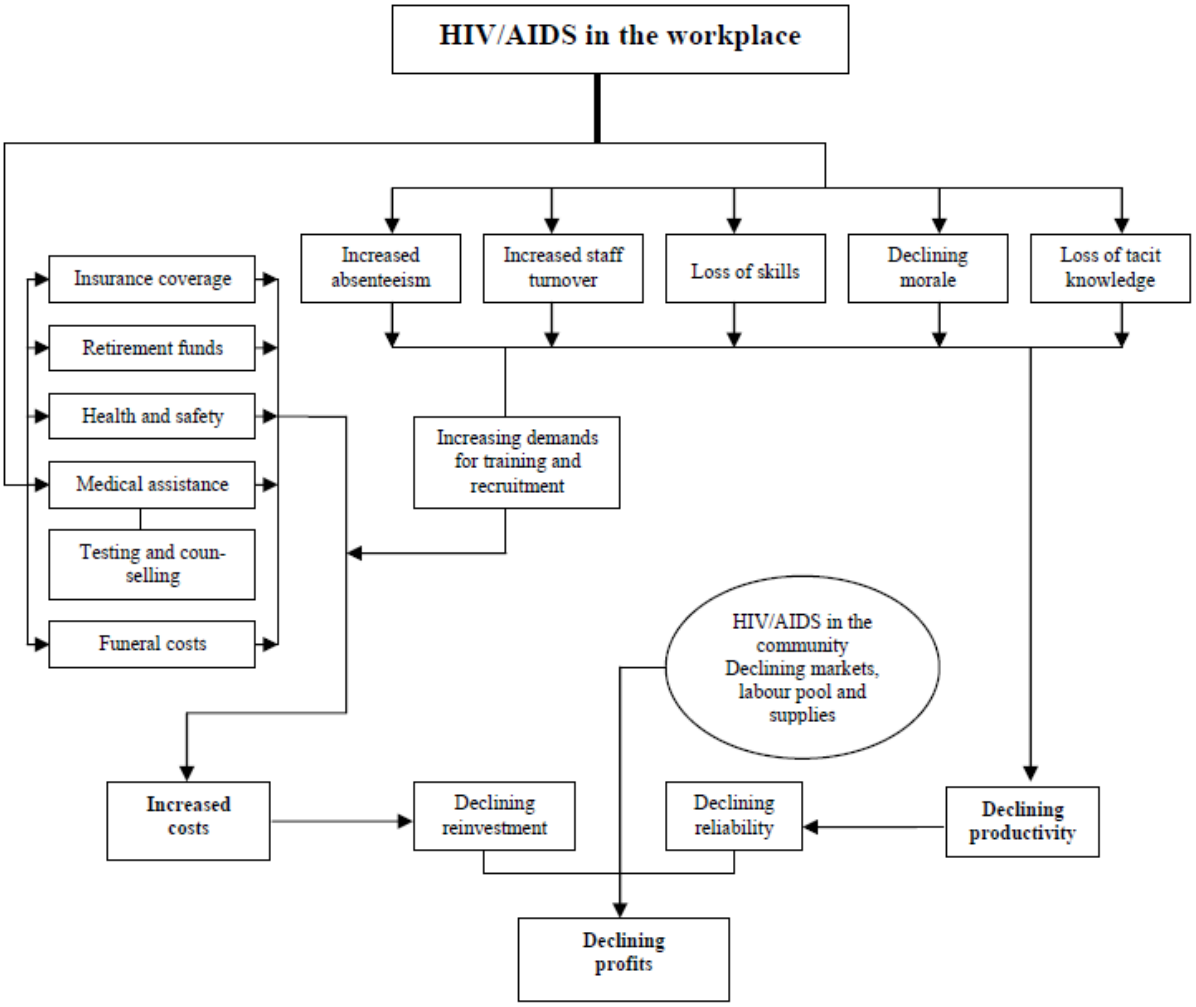
SES is one of the key factors in determining the quality of life for HIV-positive infected individuals; those with limited resources have less choice of treatment (APA, 2015). HIV status makes a negative impact on the social status of PLWHA by limiting their ability to work and

earn income (Henry *et al.,* 2015). The APA network advocates for SES-related issues and also suggested a need to report for SES in all research by focusing on the characteristics related to SES (APA, 2015). Employment brings financial satisfaction and the ability to take care of one's self without depending on another (Conyers and Boomer, 2005). Financial inability can create conflicts when basic needs are not met which then result in poor health outcomes (Kalichman *et al.,* 2015). For as long as financial satisfaction, job security or sufficient income cannot be achieved, it sometimes makes a person seek where such needs will be met (Closson *et al*., 2015). Addressing chronic disease in the workplace will lead to less economic and healthcare burden and independent financial responsibilities (Healthy Working Lives, 2013). Therefore, the impact of HIV/AIDS epidemic then goes beyond the household level. Organisations and employers are also burdened with HIV epidemic.

2.3.5 Employing organisations

An employee who is infected with HIV/AIDS can raise labour cost, lower productivity and raise investment cost as a result of consistent ill health. Rosen*, et al*. (2003) reported that an executive in a corporation operating in South Africa is most likely to have anywhere from 10% to 40% employees with HIV infection. In the absence of effective treatment, almost all of them will be severely sick during the next decade (Rosen *et al.,* 2003). Although there is a level of ill health in every workforce, particularly in developing nations, the number of severe illnesses leading to disability retirements or deaths in the coming year will be much higher than usual (Rosen *et al*., 2003). Figure 3 shows the framework to understand the impact of HIV/AIDS on organisations.

Figure 3: The impact of HIV/AIDS on organisations



Source: The Business Response to HIV/AIDS (Daly, 2000).

According to Figure 3, AIDS deaths reduce the number of workers in the organisation. In this case, the organisation would need to recruit a substitute who may be less experienced; and this may lead to a decline in productivity. AIDS deaths affect the organisation's institutional memory - the know-how - built for many years due to the affected worker's illness or death. There may also be an increase in the medical cost of organisations that have health programmes, as a high rate of HIV prevalence could increase the cost of insurance and may have an effect on the organisation's savings. The morale of workers may be affected due to workers' ill-health or deaths, and therefore, the extra cost is budgeted for training and recruitment of new workers. All these can also have an overall effect on the organisation as lower production will result in a decline in profit.

As HIV infection progresses to AIDS, staff affected are more likely to be absent from work more often. Their absence from work will have an impact on the work productivity of their organisation, especially if the staff member occupies an important position that is difficult to replace. The following sections will explore factors that could place a burden on an organisation as a result of recruiting or having staff affected with HIV/AIDS.

2.3.5.1 Absenteeism

The high rate of absenteeism seems to be one of the characteristics of the impact of HIV/AIDS on employers (UNAIDS, 2000). A comparative study of East African businesses found that absenteeism accounts for 25-54% of cost as it directly affects the quality control of products and services (UNAIDS, 2000). The period when an employee is absent from work may affect the productivity of the organisation particularly, if the employee's role is a significant one in the organisation and cannot be replaced easily (UNAIDS, 2000). Rosen, *et al.* (2003) surveyed six business enterprises using their information database to understand the overall cost of HIV infection. It was found that HIV employees added from 0.5 to 3.6 times the annual salary in costs compared to the past cost because of the reasons like HIV prevalence, absenteeism, and low productivity among HIV employees. In most cases, when a person gets to know about being positive, shock, denial and other emotional reactions may set in, and as a result, they may be absent from work for some period (Peter, 2011).

Companies also lose substantial costs on absenteeism which consequently affect productivity, staff morale, and profitability (UNAIDS, 2000; Peter, 2011). On the other hand, some workers may not want to take time off when they feel ill due to anticipated disciplinary action, cultural attitudes and stigma as they avoid being tagged as 'being lazy' or someone unable to perform efficiently as compared to other colleagues (Buck *et al.,* 2011). Meanwhile, the workplace or organisation is expected to have a range of policies that could be used to manage absenteeism and return-to-work. However, those policies may be viewed as unhelpful and too complex to support staff needs (Buck *et al*., 2011). Provision of workplace services (e.g. health

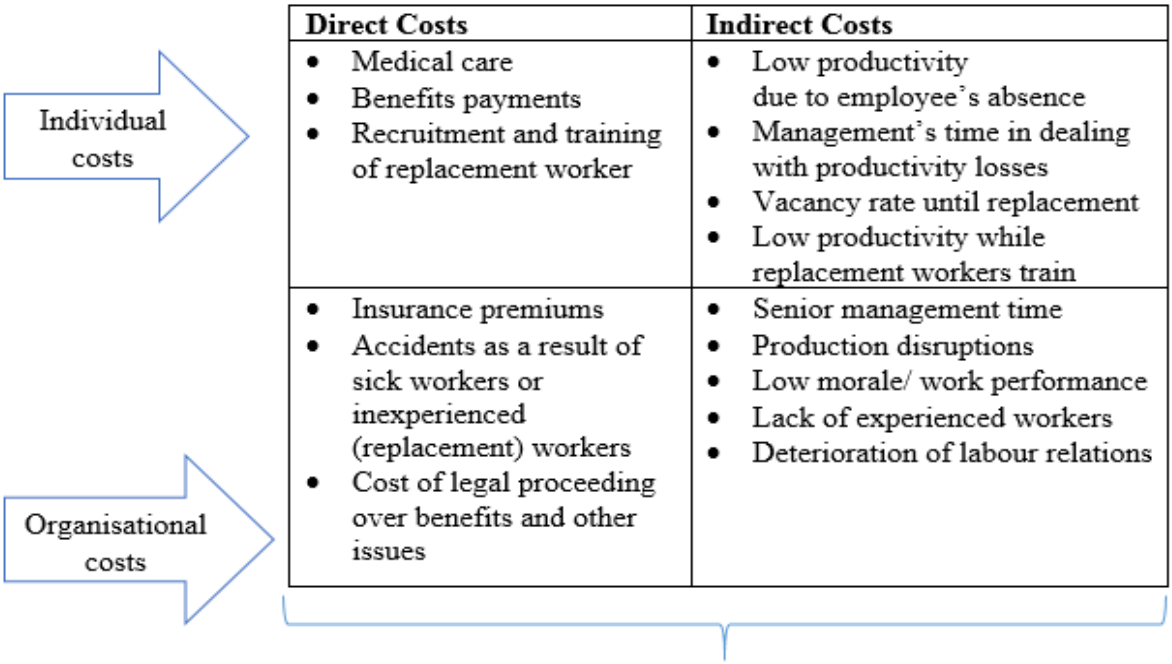
clinic, counselling unit etc.) in addressing health needs of workers serve to reduce absenteeism and inconsistency at work (Buck *et al.,* 2011).

Arnold, *et al.* (2010) proposes a model known as the Work Attitude Model to understand how clusters of feelings, beliefs and behavioural intentions have effects on work productivity and performance in an organisation. While job satisfaction is primarily concerned with the job or the work a person undertakes in an organisation, commitment shows the relationship between the individual and the organisation (Arnold *et al*., 2010). The stronger such a relationship is, the higher the organisational commitment will be (Jones and King, 2014). However, when ill-health prevents such a strong relationship, job performance, absenteeism and turnover become affected. This may also increase the financial cost of an organisation as will be discussed below.

2.3.5.2 Financial impact on an organisation

AIDS has forced organisations to spend more time coping with low productivity in their organisations, and to consider the difficult legal, social and political issues surrounding the epidemic (Rosen *et al*., 2003). For example, organisations face certain pressures from the governments and non-governmental organisations to tackle AIDS by providing jobs and additional money for victim's families. It shows the financial and the labour cost of AIDS-related illnesses. The cost implications of HIV/AIDS in the workplace can either be direct or indirect costs. Figure 4 details these costs of HIV/AIDS to employers.

Figure 4: The cost of AIDS to organisations/employers



Source: Rosen, et. al. (2003)

- Direct cost

Figure 4 above shows that the Direct cost includes the replacement cost, operational cost, and benefits or allowances. It also covers medical care of the employee especially when an employee is a member of a national health insurance scheme and organisations having health programmes may be affected by substantial medical costs (Rosen *et al.,* 2003). In other situations, medical expenses and training costs will increase while worker's productivity decreases (UNAIDS, 2000). Retirement benefits may become more expensive when the person retires based on disability or the cost incurred when an employee dies (Rosen *et. al.*, 2003). There is a demand for training replacement staff when an individual infected with HIV is not able to continue with work; this will also affect an employer's financial cost and loss of skills (UNAIDS, 2000; Rosen *et al.,* 2003).

- Indirect cost

Indirect cost on the employer is as a result of the loss of productivity through morbidity or mortality; hence, HIV/AIDS does not only affect productivity but profitability among

organisations according to the United Nations Department of Economic and Social Affairs/Population Division (UNDESA/PD, 2016). HIV affects young productive age. It also reduces company productivity in the case of death (Rosen *et al*., 2003). There may also be a situation where the organisation may have to replace an experienced worker with a less experienced worker, resulting in workers' reduced productivity (Rosen *et al*., 2003). In other situations where there is limited skilled labour, it does not only affect the training cost but the demand for higher wages may be involved (UNAIDS, 2000). The morale and productivity of other workers may be affected if HIV employees fall ill frequently (UNDESA/PD, 2016; Peter, 2011). Absenteeism also brings extra work for 'healthy' workers who stand in for sick workers, and more compensation costs will be paid by the employer (UNDESA/PD, 2016; UNAIDS, 2000). This will increase work stress of 'healthy' workers as a result of long working hours and consequently cause a decline in the quantity and quality of production, and job satisfaction (Arnold *et al*., 2010).

The impact of HIV/AIDS discussed shows the concerns of HIV/AIDS in the workplace and more devastating effects on organisations as a result of HIV epidemics. A study by Liu, *et al.* (2012) investigated the attitude of employers towards hiring a positive-HIV person and showed to be highly negative because of the concern with their work performance and HIV-related stigma.

2.4 Stigmatisation

HIV has been linked to stigma from its onset (Stolley and Glass, 2009). It remains a highly stigmatised condition for PLWHA and their caregivers globally (French *et al.,* 2015). AIDS is understood and interpreted in several ways in diverse social settings, but it is identified as a disease that predicts one's lifestyle.

Stigmatisation and discrimination against PLWHA are very common, especially in developing nations. In Nigeria, the majority of the population are attached to conservative religious beliefs, and immorality is believed to be the major cause of HIV/AIDS (Nasidi and Harry, 2006). People

living with HIV face discrimination in several ways, such as loss of job or refusal to provide healthcare services for an infected person as a result of a low level of knowledge and misconception of transmission (Nasidi and Harry, 2006). Olalekan & Oyekale (2012) reported on the perception of healthcare workers towards PLWHA and found that more than 70% of healthcare workers believed HIV patients should be separated from other patients to avoid transmission, while 70% reported that the HIV status of any clients must be disclosed before accessing health facilities. Perceived stigma from healthcare providers and health workers may compromise the consistency in accessing treatment (Patterson *et al*., 2015). Stigma often discourages PLWHA from accessing healthcare facilities, and as a result of stigma, PLWHA are prone to substance abuse and suicide (Nasidi and Harry, 2006).

Furthermore, stigma affects PLWHA regardless of their sexual identity or length of diagnosis (McDonald *et al*., 2016). Studies (Cramer *et al*., 2015; Hubach *et al*., 2015; Closson *et al.*, 2015; Li *et al.,* 2015; Nasidi and Harry, 2006) have reported stigma against people regardless of their sexual orientation. Stigma prevents an infected person without a partner from having a partner that they desired because of the fear of rejection (McDonald *et al.,* 2016; Hubach *et al*., 2015). Evidence (Lee *et al.,* 2015) shows that revealing one's HIV positive status is easier when disclosing to other people who are also seropositive than when they are not sure of others' HIV status. The study also reveals that carers of patients with HIV/AIDS may also be stigmatised due to their association with an infected patient, an act called courtesy stigma.

To avoid stigma, PLWHA conceal their status and maintain their relationships within their social groups (McDonald *et al.,* 2016). They also try to minimise any social stigma associated with their illness to reduce the likelihood of their identities being characterised with their condition (Bowling, 2009). Hence, individual's situations and interpretations of their situations influence their decision to disclose their HIV-positive status. For example, depending on an individual's socio-cultural background, illness may be seen as an inability to perform effectively or a sign of weakness (Buck *et al.,* 2011). People can also conceal their illness and avoid interactions with people or exclude themselves from their social groups when the illness is

discovered. This may then cause loneliness, depression, and lead to reduced support (Peter, 2011).

Nonetheless, effective intervention has been recorded through increased awareness and educational campaigns using various stakeholders and organisations and also media platforms to create awareness contradicting the myths and the misconceptions of HIV infection (Nasidi and Harry, 2006). However, more still needs to be done in the workplace as the opportunity to return to work after diagnosis is increasing among PLWHA. The degrees of family responsibilities and financial difficulties were associated with resuming work after diagnosis particularly among low-income countries (Sadoh and Sadoh, 2009). Disclosure of HIV-positive status to an employer may then be necessary to have access to support. Disclosure is increasingly advocated due to its impact on reducing transmission of diseases (Ssali *et al.,* 2010; Mayfield *et al.,* 2008; Li *et al*., 2015).

In the UK, the Equality Act 2010 does not make it compulsory for PLWHA to disclose their seropositive status in the workplace except in very limited situations; it is then illegal for a potential employer to ask a potential employee about their HIV status before a job offer (National AIDS Trust, 2016). Notwithstanding that, disclosing at work may be necessary if a work adjustment is expected from an employer. A modified American with Disability Act (1990) brought PLWHA into the Disability Act, and an individual requesting employment support must be able to disclose their positive status before support/adjustment is given. However, this leaves a potential risk of discrimination and stigma (Conyers and Boomer, 2005). The common job adjustments requested by employees with HIV include permission to meet doctor's appointments, flexible work patterns, shortening work days; these may not be accessed without a disclosure of status (Conyers and Boomer, 2005).

2.5 Disclosure of HIV status

Interactions and relationships are central to the daily lives of most people. We interact with people while shopping, banking, etc. and they can also bring some difficulties or privileges

into our lives. Some people also go further to build important relationships with friends and colleagues in the workplace (Miell & Dallos, 1996). These interactions go beyond simple interaction but can improve the emotional well-being of individuals (Miell & Dallos, 1996). A social relationship could develop through social interest rather than from personal or professional networks. It is usually formed between an individual and an entity; however, it could also be formed between two people. Some level of interaction exists but not as intimate as the relationship with the members of our family. It is also not a professional relationship that is work-based; however, social interaction could be developed with a colleague at work which could go beyond work-related interaction. As interactions are central to our daily lives, social interaction could meet the emotional, materials and health needs. Meanwhile, people filter out or narrow down who they want to relate with intimately. As the relationship goes through stages, it considers a visible attitude of a targeted individual or group, and then moves into internal values and the personality traits. The development of relationships involves sharing personal information (disclosure) about self, view of others and increasingly builds a body of knowledge with both parties (Miell & Dallos, 1996). PLWHA select who they want to have a close relationship with, who they want to share their information with and what information can be shared at a given time.

While PLWHA may become more selective when choosing relationships, not relating with others may result in isolation and loneliness. Isolation and loneliness as a result of living with HIV/AIDS may increase negative feelings such as sadness and depression and may also lead to a person's physical and intellectual deterioration (Miell & Dallos, 1996; Tzouvara, Papadopoulos and Randhawa, 2015). Due to these effects, people with HIV evaluate their decisions critically before disclosing their HIV positive status to another. A substantial amount of time can be spent on the state and the development of previous and present relationships with people, such as what is disclosed and what is left undisclosed (Miell & Dallos, 1996).

Disclosure of personal information has been studied for a long period where evidence has established that disclosure could build and maintain relationships (Sadoh and Sadoh, 2009;

Olagbuji *et al.,* 2011; Ezegwui *et al.,* 2009; Okareh *et al.,* 2013). Status is a social construct that categorises groups according to their social roles, prestige, or worth, with an assessment of whether a person deserves to be treated with greater respect or not (Phillips, Rothbard and Dumas, 2009). Literature that reported self-disclosure of the status states that the more intimate information is disclosed, the stronger an interpersonal relationship becomes (Chaudoir and Fisher, 2010; Toth and Dewa, 2014).

Disclosure may not be embraced when other people's perception could judge the person's competency and suitability to perform or maintain a particular role. Therefore, a strategy of managing the information before it goes beyond the required boundary (work or non-work places) could be worked out (Phillips, Rothbard and Dumas, 2009). Concealing personal information is an important theoretical perspective for understanding the dynamics of self-disclosure in the workplace (Toth and Dewa, 2014), with some literature establishing that not all disclosure in the workplace brings benefit but HIV disclosure can serve as a means of coping with the diagnosis (Odimegwu, Adedini & Ononokpono, 2013; Fesko, 2001; Breuer, 2005).

As discussed above, it might be easy for people with HIV to disclose their status to their close friends and relatives but prove to be much harder when it comes to disclosure in the workplace, as will be discussed below.

2.5.1 Disclosure in the workplace

Disclosure can be a way of coping with HIV diagnosis. Coping is a process of realising and recognising that a 'normal' situation has switched to an 'abnormal' situation and there is a cause for an adjustment (Barnette and Blaikie, 1992). The emotional, intellectual, human and material resources contribute to the adjustment to such situation (Barnette and Blaikie, 1992). One of the coping strategies may be to develop a social relationship to meet some specific needs. Social and personal relationships are different; the relationship between people in a long-term relationship and some in a passing exchange will be different (Miell & Dallos, 1996).

Communications constitute the building blocks of personal relationships as information is being shared (Miell & Dallos, 1996). Meanwhile, disclosing personal information in the workplace may influence discrimination.

People with chronic illnesses and disabilities frequently report discrimination in employment as a result of disclosure at work, which may consequently mean they are treated differently and the information provided may be used against them in the future, according to the belief that *information shared cannot be taken back* (Toth and Dewa, 2014). Gossip, derogatory statements and discrimination are common experiences or perceived experiences of people with chronic illness (Toth and Dewa, 2014). Given this report of experienced, perceived and anticipated discrimination and stigma in the workplace among people with concealable and invisible illness, they chose not to disclose their conditions before being offered a job (Henderson *et al*., 2012). For some jobs, disclosure may be compulsory and obligatory due to the type of job or the safety of the person (Henderson *et al*., 2012). Such individuals may be in the dilemma of what information to disclose? How much of it should be declared? Will colleagues accept them or misinterpret the cause of their illness? Will they abandon or gossip about them? Or interpret every expression of their emotions as symptoms of their illness, e.g. in the case of mental health problems as drug abuse? Or what will be the impact of disclosure on their employment status?

In some cases, people make false disclosure of their illness to disclose a condition that looks more acceptable than what they have, for example, an employee with mental health issues finds an alternative label (e.g. stress or depression) to describe his/her illness (Buck *et. al.*, 2011). Disclosure of any disability is also dependent on the type of organisation, culture and their perceptions of disability (Jans, Kaye and Jones, 2012). Verbal self-disclosure may be beneficial for an individual who lives with concealable stigmatised identities if the perception of his/her working organisation is positive (Chaudoir and Fisher, 2010). HIV disclosure in the workplace requires the process of evaluating a confidant to disclose to but may have a long-term impact (e.g. psychological distress, social support) on the individual. However, to further

disclose in the future is dependent on the experience and feedback of the previous disclosure, which means a person that experiences a positive disclosure outcome could disclose more than with negative outcomes.

Disclosure is a personal, multi-faceted, critical and complex decision (Mayfield et al., 2008), which is based on trust as a significant aspect of any form of disclosure of any concealable disease (Toth and Dewa, 2014). The next section will use the word ‘concealable’ or ‘invisible’ illness interchangeably for an illness that cannot be observed physically without disclosure of the illness. For example, it is easier to identify physical disability of someone having a mobility problem than someone having a mental health problem, cancer or a diagnosis with HIV.

2.5.2 Disclosure of chronic illness in the workplace

The ability to conceal an identity is dependent on the nature of the illness and experience of an individual. This identity is different from people who bear a visible illness such as a blind person or someone having a mobility problem. People with an invisible illness then have the choice to decide how, when, where and to whom they can disclose, not disclose or signal their identities. However, some chronic illnesses can be easily hidden at first, but as they progress, they become noticeable.

Babcock (1998) proposes the influence of disease progression on disclosure. It establishes the need to disclose based on the progression of the illness (Kalichman, 1995) when the condition can no longer be kept a secret. Frequent admission to hospital or a decline in health might prompt disclosure (Serovich, 2001). The relationship between disease progression, length of time of diagnosis and disclosure are well documented in several studies (Salami *et al*., 2011; Okareh *et al.,* 2013). However, due to advancement in the treatment of most chronic diseases, individuals are not exhibiting the same pattern of decline in their health. The state of health of people living with chronic disease could influence their decision to resume work after diagnosis.

Across various literatures (Phillips, Rothbard and Dumas, 2009; Jans, Kaye and Jones, 2012; Henderson *et al.*, 2012), people's illness is perceived in two ways: visible illness or invisible/concealable illness.

Visible Illness

Disclosure of a stigmatised illness in the workplace has been documented in the literature (Toth and Dewa, 2014; Makhado *et al.,* 2015; Jans, Kaye and Jones, 2012). Visible illness may be characterised as a noticeable illness, for example, those using wheelchairs, white canes, or the use of other assistive devices can be seen as having visible illness or disability (Jans, Kaye and Jones, 2012). It may be difficult to conceal a visible image of self, such as race or gender, but revealing such image may provide more details about such an individual (Phillips, Rothbard and Dumas, 2009). This is the case when an individual reveals an invisible illness in the workplace. Although this study focuses on revealing invisible or concealable information, related research has reported that people conceal their personal information such as sexual orientation, mixed-race marriage and specific social groups to prevent stigma (Phillips, Rothbard and Dumas, 2009). Individuals with stigmatised characteristics such as the visibly disabled avoid stigmatisation by managing what information to disclose (Phillips, Rothbard and Dumas, 2009).

A study was conducted by Jans, Kaye and Jones (2012) among 41 successfully employed people with physical disabilities and gainfully employed for at least five years. They found that most participants recommended that discussing disabilities with an employer is critical, especially when support is required, and their disabilities are not hidden. The visibility and the level of stigma associated with an individual's condition determine the timing of disclosure in the workplace (Jans, Kaye and Jones, 2012). This may not occur in some cases where, despite the visibility of illness, the individual still feels details of their disability will not be discussed until the need arises. Visible disabilities may require disclosure before or at an interview, or maybe when the job is offered or after probation. However, some may not disclose when it does not affect them and their job performance (Jans, Kaye and Jones, 2012).

When disclosure of such disability is made, it gives the employer understanding of what the person is capable of doing and how their disabilities will not affect doing their job well (Jans, Kaye and Jones, 2012).

Work adjustment or support accommodation may not be accessible if an individual does not disclose his/her illness in the workplace (Toth and Dewa, 2014) and could reduce the ability to request reasonable support in the workplace or to make a claim of any direct discrimination when such happens as a result of disclosure (Henderson *et al*., 2012). Public health policy has improved the rights to fair treatment in the workplace for people with chronic illnesses and disabilities, especially in developed countries (Jans, Kaye and Jones, 2012). Work support or adjustment is defined as a reasonable adjustment that makes it easier for a qualified applicant or an employee to perform his/her duties in full capacity (Conyers and Boomer, 2005). It covers, for example, provision of equipment, modification of work schedule, obtaining permission to attend a doctor's appointment and transportation. How then is it easier for someone with an invisible illness to access support in the workplace?

Invisible illness

Concealable disability is an invisible disability that is not noticeable by others, or simply, a hidden disability (Jans, Kaye and Jones, 2012). An invisible disability gives an individual a choice to either disclose such disability or not and while some could disclose as early as they are aware of their illness, some disclosed when they had spent some time in their workplace, and others did not disclose at all (Jans, Kaye and Jones, 2012). Consequences of disclosure in the workplace to employers or work colleagues may include the risk of losing a job, psychological distress, or limited job promotion (Jans, Kaye and Jones, 2012).

Disclosure of illness is achievable within a social interaction but could result in devaluation of an individual's identity in the workplace (Toth and Dewa, 2014). Public health policy has advocated protecting people with concealable illness from any form of discrimination in the workplace and to access available job accommodation (Jans, Kaye and Jones, 2012).

However, people with stigmatising health issues which are invisible often live in constant fear of someone discovering their illness thereby resulting in non-disclosure of their illness in the workplace (Toth and Dewa, 2014). Perceived job insecurity and limited knowledge of their rights could limit disclosure and support in the workplace (Toth and Dewa, 2014). Evidence has shown that lack of disclosure of health issues in the workplace could limit workplace support and accommodation (Fesko, 2001; Toth and Dewa, 2014; Henderson *et al.*, 2012; Jans, Kaye and Jones, 2012), and consequently affect work performance and adherence to treatment (Jans, Kaye and Jones, 2012; Toth and Dewa, 2014).

There are some stereotypes associated with disclosing an illness at work; these stereotypes could affect the person's psychological state as people with an invisible illness may be perceived as incompetent in their job (Toth and Dewa, 2014). In some cases, it might be difficult to trust or believe someone with an invisible condition as it is not physically seen. Buck, *et al*. (2011) reported how participants in their study view some specific circumstances, such as having cancer or infectious diseases as being acceptable when taking time off work, while people with conditions such as HIV are not perceived as needing it.

A study (Toth and Dewa, 2014) among people with mental disorders found that colleagues felt that they were faking or trying to manipulate the welfare system and as a result, seeking help was delayed in the workplace. Buck, *et al.* (2011) explained the problems faced by people with chronic conditions who needed to take time off work. They explained that the sick people need to prove that they are 'ill' before their request is accepted, although an individual's reputation and work performance could allow management to decide whether it is a genuine request or not. In a situation where an employee has to stay in the home throughout the sick leave for fear of being seen by his/her work colleagues, it makes it impossible for some to request sick leave. Meanwhile, individuals based their decision to disclose on the support required but concealing of one's condition can be a preferred choice in a situation where help may not be forthcoming.

Disability is viewed differently; society places more importance on one chronic disease than the other and most people with physical challenges get noticed easily and get the help they need compared to someone with an invisible illness. PLWHA may have a different experience of workplace disclosure compared to other illnesses mentioned earlier. This is because HIV is highly stigmatised, and disclosure of such a stigmatised condition in the workplace may result in negative consequences for employees living with HIV/AIDS.

2.6 HIV disclosure in the workplace

Disclosure varies among individuals living with HIV/AIDS. The common disclosure pattern is the disclosure among spouses or sexual partners. A study (Muhimbuura *et al.,* 2014) shows that participants preferred spousal disclosure due to trust, and the necessity to discuss safer sex. Family and friends' support also plays an important role in terms of encouraging and supporting the infected person (McDonald *et al.*, 2016). Although there are inconsistencies in the evidence of gender disclosure globally, it is most reported that women are more likely to be aware of their status through routine HIV testing during antenatal health services (Patterson *et al.*, 2015). This makes women more likely to be aware of their status than men.

HIV disclosure can be made to healthcare professionals to receive required health support. McDonald, *et al*. (2016) report an increased 'doctor-patient relationship' as their major source of health support, but it is also dependent on the length of diagnosis of the patients, a high level of trust and the knowledge of their healthcare needs. Support from HIV-positive peers is also provided when disclosure is made. HIV-positive peer supporters are groups of trained individuals with HIV that provide support for people living with HIV in their home (Lee *et al*., 2015). The support rendered may include assisting other HIV persons with some basic house chores, supporting care and treatment, counselling and providing advice on accessing the correct and needed care. Other HIV-positive colleagues working with PLWHA have reported that working with other PLWHA has improved their psychosocial health and a sense of high esteem of relevance (Lee *et al*., 2015).

Research relating to workplace disclosure reported that 33% of PLWHA disclose to their employers, while staff with managerial positions are eight times more likely to disclose at work than non-managerial positions (Conyers and Boomer, 2005). The knowledge of employers about the mode of HIV transmission can encourage a fair and appropriate employment decision to help HIV-positive individuals in the workplace (Mayfield *et al*., 2008). According to Jones and King (2014), managing HIV in the workplace is critical, as psychological and physiological aspects of life are affected, and as a result, it impacts on one's identity in the organisation. Living with HIV in the workplace may be a challenging experience due to anticipated consequences, discrimination and stigma attached to HIV/AIDS (Henry *et al*., 2015; Olalekan & Oyekale, 2012).

There are consequences to HIV disclosure in the workplace, and such consequences do differ among individuals (Henry *et al.*, 2015); the decision to disclose in the workplace should be made carefully (Mayfield *et al.,* 2008). Several types of research have reported positive outcomes of disclosure (Zou *et al.,* 2009; Brown *et al.,* 2011), while some have regretted their decision to disclose their seropositive status (Henry *et al.,* 2015; Afolayan, Wakeel and Donald, 2014). Ssali, *et al.* (2010) and Emlet (2008) reported a limited disclosure in the workplace. Meanwhile, HIV disclosure may influence health education and advocacy purposes. People living with HIV/AIDS may be in situations where disclosure could be the best choice. It could, however, have an emotional negative consequence because the decision is a complex one in real life (APA, 2015). When it is possible to avoid disclosure, non-disclosure is embraced.

2.7 Non-disclosure of HIV status

Living with HIV in the workplace may not be an easy experience due to anticipated consequences, discrimination and stigma attached to HIV/AIDS (Henry *et al.,* 2015; Olalekan & Oyekale, 2012). The fundamental reason for non-disclosure is the perceived fear of negative consequences (Closson *et al.,* 2015). A negative attitude towards disclosure will produce weak intentions and as a result, the disclosure of HIV positive status will be impossible.

Nonetheless, non-disclosure could be of significant benefit to people living with a stigmatised condition if they perceive the risk of disclosure outweighs the benefits. McDonald, *et al*. (2016) argues that non-disclosure of illness may serve as a coping mechanism for an infected individual. A coping mechanism may be dependent on an individual and the resources available (Cramer *et al*., 2015). However, coping could be difficult when an individual is faced with psychological distress after disclosure (Henry *et al*., 2015).

Apart from protecting one's identity by not disclosing one's status, it avoids feeling guilty, distressed or degraded (Closson *et al*., 2015). In a study conducted among PLWHA in Australia, it was reported that PLWHA do not want to think about their HIV-positive status or prefer not to disclose to anyone and thus result in self-management of the disease (Closson *et al*., 2015).

Non-disclosure may also be embraced because the employee's job may be at risk because of their status. A study (Lim and Loo, 2000) was conducted in Singapore among employers and human resource managers on their view of recruiting people living with HIV/AIDS. More than half of the participants said their co-workers would resign if they were aware of their HIV-positive status, 49% said the presence of the infected person in the workplace increased grievance and 74% said it contributed to an enormous increase in the medical insurance of the company (Lim and Loo, 2000). This shows that many employers have negatively reacted to disclosure of HIV-positive status (Lim and Loo, 2000). The attitude of employers towards PLWHA can impact on the low rate of disclosure in the workplace (Conyers and Boomer, 2005).

Similarly, the public's view and perception of PLWHA and the misconceptions and myths about transmission could make management of HIV difficult, or disclosure impossible, for an infected individual. For instance, a large survey assessing 987 participants from two Nigerian communities and their reaction towards PLWHA revealed that more than two-thirds (67.4%)

of participants believed they would avoid co-workers in their workplaces that are HIV-positive (Odimegwu, Adedini & Ononokpono, 2013).

The next section discusses the theories that were considered for use in this thesis. These theories were selected as being relevant because they have been used in HIV/AIDS social/behavioural research. Bryman (2012, p. 20) reported that theories are important in research because they are capable of providing 'a framework within which social phenomena can be understood and research findings can be interpreted'.

2.8 Exploration of theories on HIV disclosure

This section outlines relevant theories which form the conceptual framework of this thesis. Since the late 17th century, the biomedical model has been the common approach used in explaining health and disease (Anciaes, 2017; Bowling, 2009). The biomedical model focuses on illness as a physical problem that leads to changes in the body's image and function but can only be addressed using medicine (Anciaes, 2017; Bowling, 2009). This type of model excludes a social approach as a way to address illness. In the 20th century, the social approach also focused on ways to address illness and chronic diseases using social determinants of health (Anciaes, 2017). The idea that illness is related to social factors has continued to gain popularity since the 1990s. Social scientists then distinguished between the medical concept of illness and subjective feelings and perceptions of the disease. Evidence shows that people can be diseased according to medical indicators without actually feeling sick or ill (Bowling, 2009). Such can be attributed to people living with HIV: although their condition is incurable, it can be managed for a long period of time when treatment is adhered to.

HIV is a medical condition without cure but can be managed using a very effective drug such as an antiretroviral treatment that enables most PLWHA to live longer and have a healthy life. Recently, the management of HIV has focused more on the social aspect as stigma is associated with an increase in the epidemic (Barnette and Blaikie, 1992). Stigmatisation can result in non-disclosure of HIV positive status and denial of diagnosis which not only affects

care and treatment but has a substantial implication for prevention (Senyalo, Maja & Ramukumba, 2015).

HIV disclosure has a psychosocial impact on the lives of people infected with HIV/AIDS and that of the public (Chaudoir and Fisher, 2010); it may also promote an emotional support when disclosure is made. To understand stigma and disclosure as a means of understanding the health and well-being of people living with HIV, some related theories will be discussed. Then, a conceptual framework will be discussed to show the process of making a decision to disclose in the workplace.

2.8.1 HIV as a stigmatised condition

HIV is a stigmatised condition that affects the general well-being of PLWHA. To avoid stigma, an individual may minimise their relationships with others so that their identities will not be characterised based on their condition (Bowling, 2009), as explained earlier in this chapter. Social identity theory explains the importance of the choice to be identified as a member of a certain group and the impact of stigma on the choice of membership.

2.8.1.1 Social Identity Theory

Identity is an important concept in social psychology and forms both psychological and sociological characteristics of an individual. Social identity is based on an assumption that everyone belongs to a social group category (Worchel *et al.,* 1998). One way of understanding why people do the thing they do is because of who they think they are - their identity (Korte, 2007). Social Identity Theory (SIT) focuses mainly on human behaviour. It explains social contrast in three ways: social identity as a *rational term* that defines who we are based on our similarities and differences; as a *shared social action*, and as a *collective* product of our shared history and present. People tend to categorise themselves into groups - ‘us’ (in-group - the group they belong to) and ‘them’ (out-group - the group they do not belong to) - to gain a greater sense of who they are, but this has consequences for self-esteem, prejudice,

stereotyping and stigma (Briesacher, 2014). An illness may define a group, and for PLWHA, they may categorise themselves into a group as a result of how they see others perceive them.

Categorisation comes into play as psychological processes organise an environment into categories and groups that seem similar, and identifies differences between categories (Worchel *et al.,* 1998). An assumption says we choose to have a relationship with people who have similar interests, and physical attractiveness (Miell & Dallos, 1996). At a basic level, SIT categorises, identifies and compares things for our understanding. For example, people are socially categorised by race, religion, gender or nationality as this often helps in our understanding of things, and in the same way, people living with HIV may be categorised and this category may sometimes strengthen social isolation. Sharing information within an 'in-group' may be easier and attract fewer negative consequences compared to sharing information to an 'out-group'. Hence, people living with HIV may find it easier to share their HIV positive status with others having similar status and as a result, they can manage being identified with the condition.

Meanwhile, people living with HIV avoid being defined based on their condition; this is to minimise any consequences this may bring, such as isolation, stigma and loss of job (Hubach *et al*., 2015). One of the ways to avoid this is to conceal their status and maintain their relationships within their social groups (McDonald *et al*., 2016).

Figure 5: Social Identity Theory

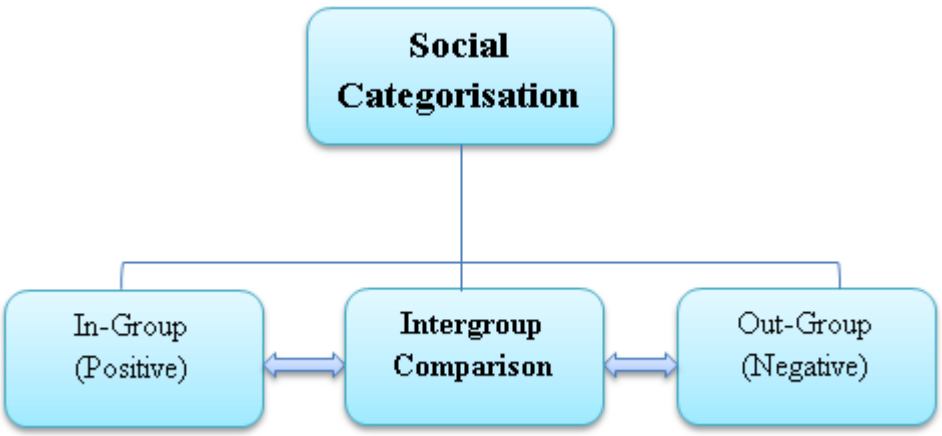


Figure 5 explains why an individual perceives him/herself similar to a group of the same background, *the we*, and the connection with other groups, *the them*. The in-group shows the similarities in a social situation while the out-group reveals the differences between them. Social Identity Theory (SIT) indicates that the members of the in-group find a negative view of an out-group to enhance their self-image (Tajfel & Turner, 1979; McLeod, 2008; Trepte, 2006).

The concept of the Social Identity Theory is used to understand how people living with HIV/AIDS view themselves differently from other groups – out-group. Henri Tajfel (1979) proposed that this action leads to stereotyping - the tendency to group things together by finding the similarities and the differences within and between groups. The public may create a perception that PLWHA may not be accepted if a disclosure is made and this impacts on the decision to disclose in the workplace. Forming an identity on the basis of membership of a group (in-group) may create boundaries with other groups. Therefore, to maintain a social group, an individual may decide what information would be provided in their chosen group so as not to 'lose their membership'. Depending on the personal information provided within a social group, a person will either maintain that status relationship or lose it (Phillips, Rothbard and Dumas, 2009). This could also mean an individual may prefer to discuss their HIV positive condition in the workplace with someone that is infected with HIV (in-group) rather than someone that is HIV negative (out-group).

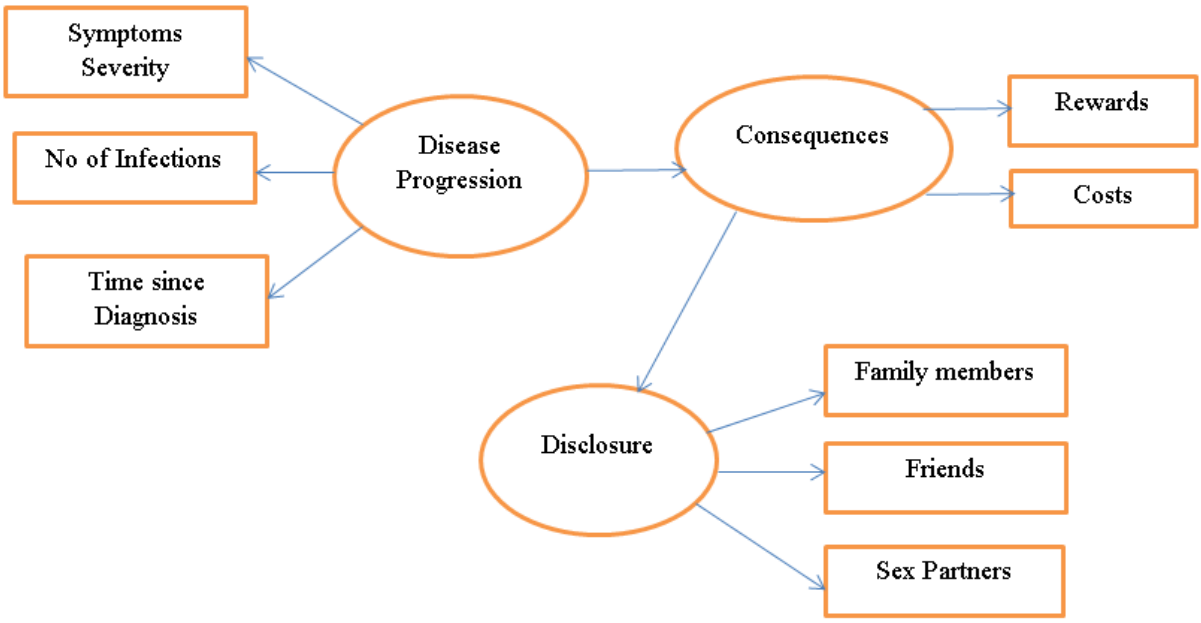
Although social identity theory has explained how people are categorised into a certain group, it does not cover circumstances where an infected person may decide to disclose to someone not categorised as in-group such as disclosure in the workplace to colleagues or the employer. Such disclosure may not be based on association, but to seek support for a reasonable adjustment to meet work demands and to manage the condition.

2.8.1.2 Disease Progression Theory (DPT)

This theory proposes the influence of disease progression on disclosure (Babcock, 1998). It establishes the need to disclose based on the progression of the HIV to AIDS (Kalichman,

1995) when the condition can no longer be kept a secret. Frequent admission to hospital or a decline in health might prompt disclosure (Serovich, 2001). The relationship between disease progression, length of time of diagnosis and disclosure are well documented in the literature (Salami *et al.,* 2011; Okareh *et al.,* 2013). However, due to advancement in treatment, HIV positive individuals are no longer exhibiting the same pattern of decline in their health, hence, the limitation of the theory. The state of health of people living with HIV/AIDS could influence their decision to resume work after diagnosis. This research explored factors that influence disclosure in the workplace such as the visibility of their symptoms. However, since advancement in treatment, PLWHA may not have visible symptoms that could influence disclosure. Where disclosure is based on disease progression or workplace support, it would incur consequences. These consequences may be rewarding or at a cost, as the Consequential theory of HIV disclosure proposes. Figure 6 below shows the link between the disease progression theory and Consequential Theory of HIV Disclosure.

Figure 6: Consequential Model of HIV Disclosure



Source: Consequential theory of HIV disclosure (Serovich, 2001)

According to the *Consequential theory of HIV disclosure* (Serovich, 2001), the disclosure is made once the benefit outweighs the cost. Costs include abandonment, divorce, low self-

esteem and uncertainty of positive outcomes associated with HIV (Okareh *et al.,* 2013; Sadoh and Sadoh, 2009). Benefits could be emotional empowerment; social support and ability to seek further help (Ezegwui *et al.,* 2009). As the disease progresses, an individual evaluates the need to disclose and the consequences become more pronounced (Serovich, Lim, and Mason, 2008). The evaluation of consequences before disclosure is important to persons that want to disclose. Sharing personal information such as HIV status may provoke anger, distress and may also impact on the personal well-being of such individual (Serovich, 2001). PLWHA may choose to reveal their status to those who pose a small risk, while limiting disclosure to those who could cause enormous harm. Disclosure of HIV needs critical evaluation and when benefit outweighs the cost, it is likely that a disclosure is made (Serovich, Lim, and Mason, 2008). PLWHA then evaluate their choice of disclosure and their expectations from those to whom they disclose.

Although, this theory is relevant to this study as it can be used to explore how PLWHA evaluate their choice of disclosure, and their expectations from those to whom they disclose, the theory fails to incorporate why disclosure is needed and what may influence disclosure.

2.8.1.3 Disclosure Processes Model (DPM)

The theoretical model developed by Chaudoir and Fisher (2010) is called the *Disclosure Processes Model* (DPM). It is similar to the Consequential theory of HIV disclosure but emphasises seeking and evaluating a trustworthy person to disclose to for the desired outcome. The theory explains 'when and why interpersonal and verbal self-disclosure may be beneficial' for an individual who lives with concealable stigmatised identities such as HIV/AIDS. It explains the two basic goals involved when taking such decisions. These are the approach goal, which emphasises rewards and the desired outcomes, and the avoidance goal, which highlights avoidance of undesired outcomes or rewards. It further explains an individual going through a process of evaluating a confidant to disclose to, and the long-term effects (psychological distress, social support) on the individual. However, further disclosure in the future is dependent on the experience and feedback of the previous disclosure made, which

means a person that experiences a positive disclosure outcome could disclose more than a person with negative outcomes.

Although this theory explains what makes a person with HIV decide to disclose, it does not consider the preconception of an infected individual or how the intention was formed before a disclosure is made. This leads to exploring the Theory of Planned Behaviour which gives a better explanation of an intention to disclose HIV status in the workplace and how the intention translates to an actual disclosure of HIV-positive status in the workplace.

2.8.1.4 The Theory of Planned Behaviour (TPB)

TPB adopts a cognitive approach that predicts individual's behaviour and behavioural intentions (Ajzen, 2011). TPB has been successfully used for studies relating to beliefs, attitudes, and behavioural intentions (Rahmati-Najarkolaei *et al*., 2017; Ayodele, 2017; Stolte *et al*., 2017). This theory is an extension of the theory of reasoned action to improve the predictive power of perceived behavioural control. The theory of reasoned action states that if an individual feels that a particular behaviour is positive (attitude), and feels that their significant others expect them to perform the behaviour (subjective norms), then the result would be higher intention (motivations) and the likelihood to perform the behaviour (Boslaugh, 2013).

Although, this theory has been used in related studies (Ayodele, 2017; Rahmati-Najarkolaei *et al.,* 2017; Stolte *et al*., 2017), there is a counter-argument against a strong relationship between behavioural intentions and actual behaviour. This is because circumstantial limitations might prevent behavioural intentions, and behavioural intentions cannot solely determine the actual behaviour where an individual does not have complete control over such behaviour. Due to the lack of control over the behaviour which was not included in the theory of reasoned action, the theory of planned behaviour was proposed with an addition of a new component called the Perceived Behavioural Control (PBC). PBC explains the ability for an individual to have complete control over their behaviour (Ayodele, 2017). People adjust their

intentions based on the estimates of their likely achievement and their ability. However they do not always have control over their behaviour due to external causes such as illness and financial position (Tylor *et al.,* 2006).

The intention is the most important antecedent of behaviour, and it is influenced by subjective norms (e.g. influence of family, peers), attitudes, expectations of future health and ability, self-efficacy and perceived control over the situation (Ajzen, 2011). In relation to this study, TPB explains how intentions to disclose develop and how this intention translates into actual disclosure (Bowling, 2009). Intentions develop based on the combination of the person's attitude towards disclosure, the pressure from others to disclose and the control they have to carry out the disclosure. The stronger the intention, the more likely disclosure is achieved, and the weaker the intention, the less likely disclosure is achieved. Behaviour can also be considered beneficial/harmful or having the potential to overcome barriers and challenges (Tyson, Covey and Rosenthal, 2014; Ajzen, 2011).

Self-efficacy is mostly used in health-related behaviour and it's a powerful predictor of measuring a good quality of life. According to Bowling (2009, p.44), self-efficacy or self-mastery is a 'personality construct that has the competency and the capacity in achieving an intended goal'. It is also the ability to be in control over one's life in the face of change. Koch Kralik and Eastwood (2002) reported on the impact of having control over one's life and how that people with disability are able to measure their life as good when they are in charge of their lives. Bowling (2009) said being in control of one's situation increases the motivation and action to make a change. Self-efficacy has been used to understand sex education, mental health and the quality of life of older people living with disabilities, and how they adapt, cope and manage their illness, and the challenges of living with the disability. In HIV research, self-efficacy has been used to explain issues such as 'self-efficacy to disclose one's HIV status, self-efficacy to discuss safe sex and self-efficacy to refuse unsafe sex' (Boone, Cherenack and Wilson, 2015; Brown et al., 2015; Kalichman, & Nachimson, 1999). Self-efficacy is also fundamental in increasing people's ability to be in control and cope with the condition. Brown,

et al. (2015) investigated the association between older people living with HIV/AIDS and their self-efficacy for condom use and HIV disclosure. It was found that older people are less able to have control over negotiating safer sex and HIV disclosure remains low among this group.

Lack of disclosure to sexual partners is associated with lower self-efficacy especially among women (Kalichman, & Nachimson, 1999). Disclosure is a challenge; it is also seen as a process that can impose stress on an infected person or be a means of coping with the disease (Rodkjaer et al., 2014). HIV disclosure can be a source of stress for some while others perceived disclosure as a coping mechanism. As HIV disclosure is an on-going process from the time of diagnosis and not a one-off event, the decision that surrounds disclosure can, by itself influence chronic stress and depression, and these can have a negative impact on the health of PLWHA (Rodkjaer et al., 2014). Coping is a complex multidimensional process and is sensitive to the environment and to personality dispositions (Rodkjaer et al., 2014). When people develop coping strategies for a stressful event, they experience fewer psychological symptoms but where there is a lack of coping strategies, people are subjected to more psychological symptoms.

Self-efficacy also explains how much control one has over their own behaviour and the confidence or the ability to carry out a particular behaviour (Boone, Cherenack and Wilson, 2015; Bowling, 2009). The decision-making regarding HIV disclosure gives an understanding of the level of self-efficacy in making a decision to disclose in the workplace without feeling intimidated to do so. Self-efficacy in HIV disclosure in the workplace also explains the ability of an infected person to have control over who needs to know about their HIV status in the workplace thereby preventing involuntary disclosure.

The nature of HIV undermines an individual's sense of self-efficacy; people with chronic problems like HIV/AIDS may lose their confidence as a result of negative outcomes of HIV disclosure. However, patients increased self-efficacy improves chances of an effective self-management and empowerment (Simpson and Jones, 2013).

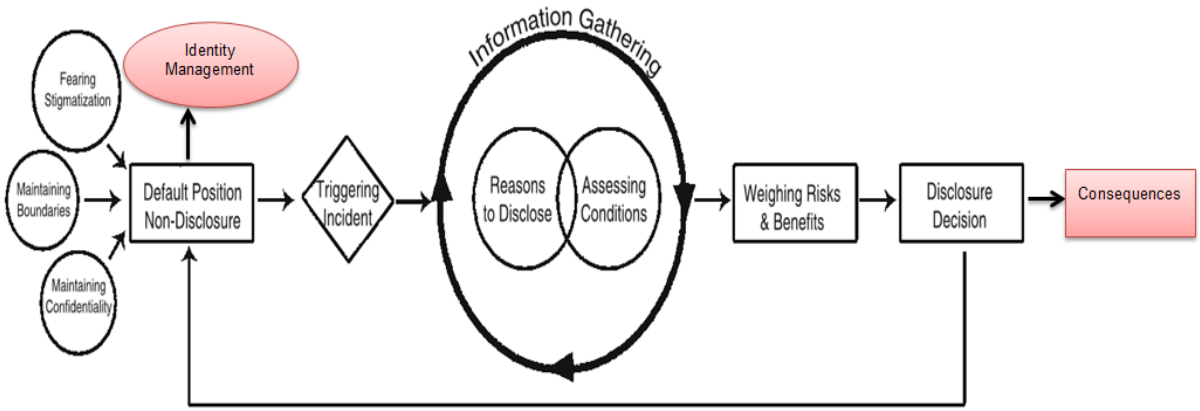
2.8.2 The Employee Decision-making model

The Employee Decision-making model developed by Toth and Dewa (2014) was used as the most relevant of the models. It attempts to describe the employee decision-making process of disclosure, together with the function of interpersonal reasons and organisation commitment in decision-making. A model provides an overall framework for understanding reality (Silverman, 2012). This model developed by Toth and Dewa (2014) incorporates various features of disclosure that could be used in various circumstances for an invisible illness. Although this model was designed for employees with mental illness, it can be used to understand the process of decision-making among people living with HIV/AIDS. It presents an understanding of the process of making a decision to disclose an illness in the workplace and the outcome of such decision. The model was modified to include *Identity management* (social identity theory) and the *consequences* after HIV disclosure in the workplace.

Conceptual framework

Based on the above discussion of relevant theories on HIV and disclosure, important issues such as relationships, trust and disclosure were explored. The following sections present the conceptual framework for this thesis as shown in Figure 7 below.

Figure 7: Employee Decision-making process of HIV disclosure



Adapted: Employee Decision-making process (Toth and Dewa, 2014)

This model developed by Toth and Dewa (2014) called *Model of Employee decision-making* used current employees of an organisation. It explains how individuals move from a default non-disclosure of their mental disorder in the workplace due to anticipated fear of stigma, to a rational reason to disclose. The *Default Position of Non-disclosure* is maintained initially to keep some boundaries, evaluate the present relationship, maintain confidentiality or for stigma avoidance. Maintaining boundaries in the workplace differentiates between work life and home life with the adoption of the belief that personal life and work life should have boundaries to maintain confidentiality. This component is also related to Social Identity Theory where people want to keep a certain identity and function within their existing group to preserve their identity but avoid stigma. At this stage, people also may form certain perceptions towards disclosure (The Theory of Planned Behaviour); the more positive the attitude is towards disclosure, the stronger the intention to disclose.

A *triggering incident* may then need to move a person from the default position to a reason/situation to disclose. Triggering incidents happen when an individual struggles to cope with work, and support is needed to balance work and health. The incident then initiates the decision-making process of gathering information about the chosen disclosure recipient (e.g. characteristics of the recipient).

The process of gathering the information, *Information Gathering*, may take a longer period of time (Toth and Dewa, 2014) depending on the triggering incidents and the degree to which it impacts on daily activities. The information gathered includes assessing the conditions and reasons for disclosure, which could be grouped into work-related, personal and interpersonal reasons. For example, personal reasons could mean disclosure as a result of correcting a misconception about the illness and building a strong relationship through mutual sharing. Interpersonal reasons could happen when disclosure is done to help or support others in a similar situation through sharing a personal experience, while work-related could be reasons such as seeking support or empathy from an employer or work colleagues.

Risk-Benefit analysis is a way of evaluating the risk and benefit involved in a decision before it is taken. This is also called cost-benefit analysis or approach-avoidance goal in the Consequential theory of HIV disclosure and Disclosure Processes Model respectively as explained earlier. It is important to note that weighing the risk and the benefits stage may be quicker when a reason to disclose is identified. When the analysis has been made (either the risk outweighs the benefit, or the benefits outweigh the risk) the person proceeds to make the disclosure or non-disclosure decision called *(Non-) Disclosure Decision.* Disclosure recipients could be employers, managers, supervisors or colleagues in the workplace. This process of deciding to disclose or not in the workplace may be needed at every stage of life of an employee living with an invisible and chronic illness. After a decision is made, there are *consequences* that follow whether an individual disclosed or not.

This conceptual framework reflects that a decision to disclose a chronic disease such as HIV, in the workplace is not a straightforward decision, as highlighted in Figure 7 above. The model has been modified to include *Identity management* and *Consequence* after a decision is made: such consequences may be beneficial or harmful. Consciousness to protect one's identity could mean that an individual infected with HIV devises a means to limit stigma by carefully evaluating the decision to disclose to others. This is detailed in Social Identity Theory. Another component added to this model was the *consequences* after a decision is made. The consequences may be beneficial or harmful. Consequences of disclosure or non-disclosure, as stated earlier, could include abandonment, stigmatisation, loss of employment and discrimination in the workplace (Ssali *et al*., 2010; Emlet, 2008).

To sum up, the above conceptual framework has incorporated components of Social Identity Theory, the Theory of Planned Behaviour and Consequential Theory to explain how a decision is formed, the condition to be accessed and the consequences of the disclosure. This indicates that the process of decision making often involves careful evaluation before disclosure is made.

2.9 Summary

This chapter provides an overview of the main potential benefits and risks associated with HIV disclosure. It examines the global and regional prevalence of the HIV epidemic and then specifically gives a detailed account of the HIV epidemic in Nigeria. This chapter also reviews studies relating to HIV disclosure. However, a limited number of studies were found investigating HIV disclosure among employed people living with HIV/AIDS. Also, the thesis setting is Nigeria. National policy over the last decade has focused on tackling the HIV epidemic and supporting those who are infected with HIV. Despite this, at present, there are no guidelines in Nigeria on the choice of employed PLWHA to disclose their status or not in the workplace. There is also limited empirical evidence on the perception of HIV disclosure in the workplace among PLWHA in Nigeria. Hence, there is a need to conduct a study which takes a qualitative approach that allows the issues truly of relevance to those affected with HIV to be investigated.

The next chapter covers the method/methodology. It explains the background to the two methodological approaches that were used to answer the research questions. It also explores the theoretical perspective that underpins this research and how this perspective is reflected in this thesis.

Chapter Three: Methodology

3.0 Overview

The choice of approach has a long history of debate in the philosophy of science (Bowling, 2009). Each branch of scientific inquiry is based on a set of theoretical perspectives or paradigms on which the research topics are based. Understanding the theoretical perspectives could provide the direction and framework from which a situation is observed.

Positivism has long been established as the main philosophy of science. It measures phenomena using a deductive approach and assumes that human behaviour is as a result of external stimuli (Bryman, 2012; Bowling, 2009). However, positivism could be misleading because it encourages laying emphasis on superficial facts without understanding the underlying mechanisms observed and what it means for the individuals (Bowling, 2009).

Social research and its methods do not take place in isolation but are formed within some contexts and the context is often dependent on the investigator's assumptions about the society (Bryman, 2012). The philosophy of phenomenology viewed that social 'facts' are characterised and recognised by the members of the social world; their 'reality is multiple and socially constructed' (Bowling, 2009). To understand the social meaning, social scientists employ theories to give an understanding of the social world, to influence what is studied and how the study findings are interpreted. Social research is informed and shaped by theories (deduction), it also contributes to theory (induction) as the findings of a study may feed into the available knowledge to which the theories relate (Bryman, 2012; Bowling, 2009).

In terms of deductive reasoning, a researcher starts with a general idea by collecting and analysing data to test hypotheses, whereas inductive reasoning begins with observations and builds up ideas which can be further tested on the basis for further observation (Bowling, 2009). As the former implies, the existing knowledge about an area of interest of the researcher forms an integral part of the background within which the social research takes place. The review of literature previously explored in chapter two helped to know what already exists and builds on it without covering the already existing grounds (Bryman, 2012). After the awareness of the existing knowledge, the researcher sought to further understand the underlying mechanisms that form some social meaning on HIV disclosure.

The literature review chapter shows briefly the perceptions of disclosure when living with an invisible condition, and the impact of such conditions on the individual, family, community and in the workplace. To understand HIV and AIDS disclosure, specifically the perceptions of people living with HIV/AIDS in the workplace, two approaches were used. The first approach, the systematic review method, provides knowledge of what exists, and the qualitative study gives an understanding of individual perceptions. Combining secondary and primary methods is an approach that not only validates the research findings but also deepens and widens knowledge (Olsen, 2004). To answer the research questions, this study used two approaches: the systematic review and the primary qualitative research as in table 2 below.

Table 2: The alignment of the two phases of this study

Phase	Aim	Objectives	Method
One	Collect and synthesise evidence from studies on HIV/AIDS disclosure among people living with HIV/AIDS in Nigeria.	(a)Understand the factors that may influence the disclosure of HIV status and its impact on people living with HIV/AIDS (b)Describe the prevalence and patterns of disclosure, outcomes, and factors associated with HIV disclosure in Nigeria	Systematic Review
Two	Explore HIV disclosure among employed people living with HIV/AIDS in Nigeria	(a)Discuss the factors that influence people living with HIV/AIDS in Nigeria to disclose or not in their workplace (b)Understand to whom those living with HIV/AIDS disclose in their workplace, and why (c)Examine the psychosocial impact and practical implications of disclosure in the workplace for people living with HIV/AIDS	Primary research: Qualitative approach

Phase one (Aim 1) collects and synthesises evidence from studies on HIV/AIDS disclosure among PLWHA in Nigeria. Furthermore, it will discuss the methods used in retrieving all

included studies, the ethical considerations relevant to the review, and the method of analysing the data and its procedures. Fourteen articles are included in the final review. The article search was between January 2000 and January 2015 and was updated in 2017 after the first ten articles were published[1]. This phase based its analysis on all the fourteen articles that are found in total.

Phase two (Aim 2) aims to explore HIV disclosure among employed people living with HIV/AIDS in Nigeria. It adopts a qualitative approach using face-to-face interviews with patients accessing HIV treatment in a hospital in Nigeria. The recruitment procedures for both the hospitals used and the study participants are developed using purposive sampling techniques. The interview employed a semi-structured method of data collection using a semi-structured interview schedule for gathering information used in answering the research question. Ethical considerations and data analysis procedures relevant to this study are discussed.

[1] Ten papers were found as at April, 2015 and were included in a paper. See the abstract of the published systematic review paper in Appendix 13 or click the link: https://www.ncbi.nlm.nih.gov/pubmed/27059370

Phase One: Systematic review

3.1 Introduction

There are two main types of review that are commonly found in scientific literature, narrative and systematic review of the literature. A narrative literature review describes and discusses the state of the science of a particular topic or theme from a theoretical or contextual point of view (Rother, 2007; Bettany-Saltikov, 2012). This type of review does not mention the database nor have specific criteria for inclusion of articles during database search but could involve critically analysing articles in published books and electronic or paper-based journals. They provide up-to-date information about a specific topic (Rother, 2007).

For the purpose of this study, a systematic review is adopted. It has a well-planned review that attempts to identify, appraise and synthesise all empirical evidence to answer a specific research question using a systematic approach and explicit methodology (Cochrane Library, 2017; Boland, Cherry & Dickson, 2014; Rother, 2007). It may produce more reliable findings compared to narrative review and can make an informed decision in a variety of disciplines and professions (Boland, Cherry & Dickson, 2014).

3.1.1 Methodology

According to Starr, *et al*. (2009) the Systematic Review Methodology was developed after Archie Cochrane's book 'Effectiveness and Efficiency' drew attention to a need to inform health service development in 1972. One of the readers of Cochrane started to collect reports of randomised trials on access to care in the area of maternal and child's health. After this collection, a need to improve clinical practice based on reliable research evidence was

identified. In response to this identified need, a computerised register of all similar studies was collected to create overall estimates in perinatal medicine. Hence, a call to establish an international collaboration to prepare 'critical reviews' of the studies was made. The example of the work in perinatal medicine led to a recognition of systematic review in the UK as a legitimate use of research and development (Peckham, 1991).

This systematic review collects and synthesizes evidence from studies among people living with HIV/AIDS in Nigeria which examine HIV disclosure, its prevalence, patterns and other associated factors, thus identifying knowledge gaps to inform further studies. To gather the evidence, theoretical and methodological decisions need to be made using secondary sources which provide a critical interpretation and enable the researcher to meet the study's main objectives (Bhatt, 2012). The systematic review (SR) was used as a method of inquiry at this stage. In this SR, the researcher has followed a realist approach where documents are generated with the use of criteria, reflecting its epistemological stance (Gidley, 2012).

A systematic review approach in health and social sciences is important because it supports policy making (such as treatment, drugs, and behaviour), supports good practice amongst clinicians, and strengthens decision making when conflicting evidence is reported (Bryman, 2012). SR has been established as an approach over several decades (Boland, Cherry & Dickson, 2014). It offers a scientific and rigorous way of addressing research problems through the use of a developed procedure (Seale, 2012). SR can also help identify bias and lack of methodological rigour (Bettany-Saltikov, 2012).

Conducting a systematic review helps to understand the existing evidence base of people living with HIV/AIDS and their disclosure experience. The chosen population, that is, Nigerians, shows significant differences from other people living with the same condition in the sub-Saharan region in terms of their socio-cultural, political and economic states (WHO, 2014a). The systematic review will help to collect and synthesise the evidence on HIV

disclosure among PLWHA and, finally, identify gaps in the literature to cover in this research and introduce further studies in this field.

In addition to the research gaps, the literature review chapter shows a lack of systematic reviews on HIV disclosure in sub-Saharan Africa and to the best of the researcher's knowledge, there is no systematic review study that had investigated HIV disclosure among people living with HIV/AIDS in Nigeria.

3.1.2 Research design

One of the criteria for a good systematic review is to be transparent with the review process (Boland, Cherry & Dickson, 2014). Research design outlines the appropriate steps employed to conduct the review. A systematic review is designed to locate, appraise and synthesise the best available evidence relevant to the research that aimed to provide informative findings (Bryman, 2012). This limits bias, misrepresentation or misinterpretation of results. Hence, the step-by-step requirement by Boland, Cherry & Dickson (2014) was used in conducting this review. The steps include defining the research questions, identifying and assessing available studies, synthesising the findings and drawing conclusions. To achieve the aim of this systematic review (see table 2), inclusion criteria were developed as shown below.

3.1.2.1 Inclusion and exclusion criteria

Inclusion criteria explain the specific characteristics a study needs to possess if it is to be included in the review, and are sometimes called *Eligibility Criteria* (Boland, Cherry & Dickson, 2014). Any study not possessing these criteria was excluded. Inclusion and exclusion criteria are recommended before conducting a review; this helps the reviewer to target the relevant studies and exclude others (Bettany-Saltikov, 2012). Here, the inclusion criteria and the aim of the review complement each other and help the researcher to refine objectives and assess if these were too ambiguous or too specific (Boland, Cherry & Dickson, 2014). It can also help the reviewer not to deviate from the overall aim and objectives of the review. Given the review aim:

‘To collect and synthesise evidence from studies on HIV/AIDS disclosure among people living with HIV/AIDS in Nigeria’

Studies were included in the review with the following inclusion criteria:

1- Language: Studies that are published in the English language only.

2- Types of studies: Studies reporting primary qualitative, quantitative or mixed methods

3- Type of participants: HIV-positive

4- Participants’ age: Adults who are over 18 years old

5- Study location: Nigeria

6- Outcome measures: Reported impact of HIV disclosure or non-disclosure among PLWHA

All the studies which did not meet the above criteria were excluded. In addition, the reference lists of already identified studies that met the inclusion criteria for potentially relevant studies were checked. Systematic reviews relevant to the topic were also screened. The WHO, Centre for Disease Control (CDC), International HIV/AIDS Alliance websites, and Africa journals/databases were also searched but these did not produce any articles for inclusion. Articles on these global websites largely focused on guidelines for health professionals on ways to inform patients about their HIV-positive status, accessibility of HIV treatment and disclosure of status to children who are infected with HIV. Those articles which looked into HIV disclosure were not carried out in Nigeria. To also increase relevant studies, conference proceedings on the topic were searched.

3.1.3 Search strategy

The search strategy is the method that identifies evidence to be included in this systematic review (Boland, Cherry & Dickson, 2014). A pragmatic approach was used in searching available evidence as will be explained below. MedLine, PsycINFO, Cochrane Library,

CINAHL, Scopus and Discover[2] were searched for primary studies using the selected keywords, synonyms or alternative terms and Boolean operators (AND, OR, and NOT). More details are found in section 3.1.4 *Screening Strategy*. The search was originally conducted between January 2000 and January 2015 and was later updated in 2017.

3.1.4 Screening Strategy

Bryman (2012) argues that the search strategy must be explicit and allow for replication; it should be based on the keywords and related terms to the research question. Hence, the keywords of the research topic were identified for easy search and to identify all related articles, such as people having the condition, the condition; HIV/AIDS, disclosure as a means of intervention and the geographical location, Nigeria. The previously mentioned electronic databases were searched using the keywords, synonyms or alternative terms, and the truncation (*) symbol was used to attract all terms. These include: (Nigeria*) AND (disclos* OR expos* OR reveal*) AND (self OR voluntary*) AND (HIV OR AIDS OR serostatus OR positive status OR human immunodeficiency virus OR acquired immunodeficiency syndrome) AND (attitude* OR behaviour* OR belie* OR consequenc* OR react* OR reason*).

The retrieved titles and abstracts were screened against the inclusion criteria. Emails were sent to authors for papers whose full-texts were not accessible online via any means possible. The use of email alerts was adopted to receive updates from journals. In addition, the reference lists of already identified studies that met the inclusion criteria for potentially relevant studies were screened. Systematic reviews relevant to the topic were also screened. The articles found from all the various ways to search databases were imported into a single reference manager file to eliminate duplicates.

Full texts of the studies identified and marked for possible inclusion were obtained. Some were obtained through the institution's inter-library loans system, emailing the author, or via experts'

[2] a database in the University of Bedfordshire-researcher's institution- containing databases relevant to health and social sciences and other fields, University of Bedfordshire, 2014.

websites such as ResearchGate. Full-text screening focused on studies that reported disclosure (or non-disclosure) of HIV status, the disclosure recipient, the reasons for and impact of the disclosure, and factors associated with disclosure. A specialist subject librarian assisted with devising the search.

3.1.5 Data extraction

This process brought relevant data into a single extracted form and stored it in a single format to support analysis (Boland, Cherry & Dickson, 2014). Using Microsoft Excel (version, 2013), an extraction spreadsheet was created to collect data from all included articles. Studies were included at face value of what the authors of individual studies reported. The extraction was divided into categories and sub-categories to answer the objectives of the review, the categories include title, aims/objectives, sample size, outcomes, and ethical procedures. Two types of data were extracted: descriptive and analytical data. Boland, Cherry & Dickson (2014) reported that systematic reviews are primarily interested in these two types of data to explain the biographic of participants (descriptive data) and the outcomes of the study (the analytical data). Data extracted from the spreadsheet was used to generate tables.

The spreadsheet data extraction of the studies was discussed during the supervisory sessions to ensure all the data were entered correctly and accurately. This is done by revisiting the inclusion criteria, collecting and synthesising the data that answered the research question.

3.1.6 Quality appraisal

A quality appraisal was conducted to assess the included studies. This assesses whether each study has been designed, conducted and reported in a manner that can be considered rigorous or relevant to the review aim. The word ‘quality’ used here refers to the quality of each study included and not the quality of the systematic review itself; the latter is discussed in *section 4.1.7.* The quality assessment tools can be applied in two ways: the numerical value/scoring system of the quality of the study, or the use of checklists (Boland, Cherry &

Dickson, 2014). In this instance, a checklist tool was used as it provides detailed information about the quality of each study.

The Critical Appraisal Skills Programme [CASP] checklist tool was used for the quantitative (cross-sectional and case series) studies to appraise the quality of the included studies (CASP, 2013; Centre for Reviews and Dissemination, 2009; Caldwell, Henshaw & Taylon, 2010). The checklist considers the internal and external validity of the included studies. In ensuring this, the checklist takes into account the following; the study design, sampling strategy, eligibility criteria, response rate, a sample calculation, data collection process, data analysis, validity/reliability, interpretation of results and consent/ethical clearance of each study, which were assessed and presented in a tabular form.

3.1.7 Data analysis

A descriptive presentation of data was carried out first and then was subjected to meta-analysis. A descriptive presentation of data is relevant to any type of data analysis as it synthesises the information of the included studies (Bettany-Saltikov, 2012). The information collected was developed into categories meeting the objectives of the research which are to collect and synthesise evidence from studies among people living with HIV/AIDS in Nigeria, and to examine HIV disclosure, its prevalence and patterns, and other associated factors thus identifying knowledge gaps to inform further studies. The categories include characteristics of the studies, outcomes of disclosure, factors associated with HIV (non)disclosure and its impacts, then contextualising the findings based on their methodological strength.

As all the studies were quantitative, a meta-analysis was carried out by assessing the statistical heterogeneity using a random-effects model, with the I^2 statistic used as a measure of inconsistency. This analysis was performed for disclosure rates of HIV status as well as for the rates of supportive reactions upon disclosure (as seen in Figures 13 & 14). The conclusion was drawn based on the quality of the study and its relevance to the existing literature.

3.1.8 Ethical considerations

Although a systematic review is an approach established over decades, the ethics of it are rarely discussed (Bettany-Saltikov, 2012; Boland, Cherry & Dickson, 2014). This has a bearing on the credibility of the findings as a review may contain studies with ethical issues and could be affected by a conflict of interest. The consent gained for an original study may not be valid at the systematic review level (Vergnes *et al.,* 2010). As ethical issues change with time and location and are very broad, this makes it difficult to have universally accepted ethical guidelines. The systematic review does not involve direct engagement with original participants' ethical assessments for all included studies. However, this was done by using the checklist tool that assesses the ethical procedures of each study. In addition, an appropriate referencing style was used to acknowledge the author (s) of the studies.

In an attempt to avoid publication bias, unpublished studies were sought (Vergnes *et al.,* 2010), which may be more likely to have ethical issues. However, studies included in the review were from peer-reviewed journals only; more details of inclusion of only peer-reviewed journals, its justification, and limitation, are detailed in 3.1.2*.1 Inclusion and exclusion criteria.* A systematic review can be said to increase the risk of including studies conducted in ethically unacceptable circumstances and may not respect ethical principles.

Phase Two: Qualitative methodology

3.2 Introduction

This phase presents the methods used in this qualitative study. This begins by outlining the theoretical perspectives of the research that underpins this qualitative study. The eligibility criteria for the study are discussed, and then the recruitment procedures used for both the hospital and the patients presented. The phase also outlines the approach used in analysing the data and the ethical issues related to the study. The phase finishes by presenting the pilot study that was carried out prior to the main study.

3.2.1 Epistemological stance of a constructivist

According to Seale (2012, p. 12), 'the truth and how it can be identified can be seen in two ways by philosophers: as instrumentalists, and as realists. Instrumentalists believe that scientific theories are useful conceptual constructs that have no truth value while realists regard scientific theories as explanatory constructs that possess a true value. What truth is and how it can be identified has been explained in various ways by philosophers through several theories such as the correspondence theory, coherence theory, social constructionism, pragmatic theory, and epistemological subjectivism/relativism theory.

Correspondence *theory* takes 'truth as a corresponding relationship between thoughts and objects which is based on objective reality and needs a rigorous process of scientific inquiry' (Seale, 2012, p.20). Thus, it is closely linked to *positivism,* while *coherence theory* identifies truth as long as it makes sense within the context it is made in (Seale, 2012).

Meanwhile, *social constructionism* takes truth as a construct by the society, through the power struggles within a community. It is constructed and not discovered and gives each participant equally valid construction of their own meaning (Seale, 2012; Gray, 2013). In this study, each participant that was included constructed their own meaning of HIV disclosure in the workplace and its implication on the decision to disclose or not in the workplace. Constructionists argue against external realities as a reflection of knowledge but rather truth being perceived as

'human perception and social experience' (Seale, 2012, p.20). Given this, a theoretical perspective linked to constructivism is interpretivism (Gray, 2013).

3.2.2 Interpretivism research

Natural and social science may differ, but both can be useful in their relevant areas to explain phenomena. Social science is ideographic as it often deals with the action of the individuals (Gray, 2013). The work of social scientists involves theoretical premises, methods, and practices for scientific work. This should be explicit and systematic in relation to research design, data collection, analysis and interpretation of the findings as it reduces bias or error (Bowling, 2009). *Positivism* describes the view that the social world exists externally and should be measured through observation, and that society should be studied like nature (Gray, 2013). On the other hand, interpretivists hold that studying a society requires an interpretative approach by seeking its *social meaning* (Seale, 2012). It also emphasises that social 'facts' are characterised and recognised by their 'meaningfulness' to members of the social world called actors (Bowling, 2009). Seeking social meaning by asking questions could uncover the 'truth' of how it feels like living with HIV/AIDS in the workplace. Interpretivism is a major positivism 'opponent' that concentrates on how culture and history interpret the social world (Gray, 2013). In seeking social meaning, our subjective experiences are involved in our social life.

3.2.3 Phenomenological approach

This approach allows the researcher to create an understanding of a specific issue from the participants involved in the study (Lu & Gatua, 2014). Naturalism is the belief that focuses on the visible characteristics of participants under investigation. However, it has been criticised for not constituting reality within the object under study and underestimates *how* participants create meaning in their daily living (Seale, 2012). In the Naturalistic inquiry, participants are only treated as a source of data without seeking to know the capacity of their interpretation and how they make sense of their own world (Gray, 2013: Gubrium & Holstein, 2012). In ethnomethodology, participants construct or translate their everyday lives' conversation to

understand the view of the world (Gubrium & Holstein, 2012). The researcher 'brackets' him/herself from previous knowledge, this is called *ontological* detachment (Gray, 2013), and uses other areas of participants' interaction (such as response, body language, and physical appearances) to infer meaning. This was employed during a face-to-face interview with the study participants as other areas of participants' interaction contributed to the data collected. More on the face-to-face interview is found in s*ection 3.2.6 data collection.*

The methodological stance for this research is phenomenology. This is used because it attempts to understand social reality in participants' views and lived experiences (Gray, 2013; Walsh, 2012). Phenomenological research is based on the paradigm that 'reality' is multiple and is socially constructed. Social scientists using a phenomenological approach are concerned with 'hermeneutics' which can be categorised into two strands: *Humanists* seek to understand the individual, their awareness and the whole context of a social situation. However, it assumes that the validity of individuals' accounts of their experience is uncritically accepted. *Interpretive* sociologists seek interpretations through the interaction of individuals that cannot be standardised across social and cultural groups (Bowling, 2009).

Phenomenology is an inter-subjective constitution of the social world and everyday social life; human beings formulate meanings based on their daily experience and understanding of their geographical location or in a certain society (Walsh, 2012). This approach is used in this study to explore the participant's world and the position from which their experience originated and is expressed in multiple phenomena (Smith, 2009). The study of participants living with HIV/AIDS is idiographic as the researcher explores the subjective experience rather than the objective generalisation of meaning or phenomenon (Walsh, 2012). Objective generalisation conceives the world as 'concrete' and makes it measurable while the phenomenologist conceives the construction of reality as an interpretation of the objects (Seale, 2012). Hence, the interpretation of the phenomenon under investigation is dependent on our subjective encounter and our consciousness of the objects (Filmer *et al.,* 2012). In this study, social

meanings were developed through the interaction of participants assigning meaning to their perceptions and experiences. This meaning is collected using a qualitative approach.

3.2.4 Qualitative Approach

As this research employed an interpretative approach by seeking participants' social meaning, a qualitative approach is adopted as an appropriate approach for this study. The overall reason for using this approach is to help in understanding participants' perceptions by collecting data about HIV disclosure among employed people living with HIV/AIDS. Qualitative methods do not manipulate research settings (Bowling, 2009). In practice, qualitative researchers often 'sacrifice' the breadth of the research for depth, which can make the external validity of data questionable but useful to give an in-depth understanding of a specific phenomenon when the existing information is limited (Lee *et al.,* 2015). Therefore, the aim of the study has not been to generalise the sample of employed people living with HIV/AIDS in Nigeria but to select a few individuals with the first-hand experience on their perception of HIV disclosure in the workplace.

3.2.5 Population, sample and sampling tool

According to Bryman (2012 p.714), 'a population is the universe of units from which a sample is to be taken'. In this study, the population was people living with HIV in Nigeria, who may or may not have disclosed their status in the workplace. Sampling is important, often owing to limited time and resources. To carry out effective research on the population of interest, the choice of sampling method depends on the purpose of the research (Bloch, 2012). In a social survey, a random selection or sample of a population will be included in the survey to make generalisation possible, and if the sample of the survey accurately represents the whole population, it is called a representative sample (Seale, 2012). However, a qualitative approach seeks to develop an in-depth understanding of human behaviour and the reasons that govern such behaviour (Creswell, 2009). Therefore, to understand HIV disclosure in the workplace, a sample of employed people living with HIV/AIDS was selected in this phase.

Sampling refers to the segment of the population that is selected for study, which is broadly divided into two methods: probability (simple random, stratified random & cluster) sampling and non-probability (quota, snowball, volunteer, theoretical, case study and maximum variation) sampling (Seale, 2012). A probability sampling ensures that all potential participants have an equal chance of being selected. This could provide a representative sampling of the whole population, while non-probability sampling cannot provide such an equal opportunity (Seale, 2012). Non-probability is, however, a useful sampling method when investigating people that are 'unknown' to the public or can be difficult to get their sampling frame (Seale, 2012). A sample frame is the total number of the population of interest either individual, institution, or objects (Seale, 2012). In a non-probability sample, representative sampling is not desired as the study aims to have more insight into the perception of HIV disclosure in the workplace among PLWHA. Therefore, it is a qualitative exploratory study.

Exploratory research is used as a flexible research design that considers many different aspects of a problem (Kothari, 2004). This characteristic is often used in qualitative research (Seale, 2012). Hence, this study employed non-probability sampling techniques as the study investigates PLWHA that may be stigmatised and living in a culturally-sensitive society. As mentioned above, non-probability sampling has different sampling methods. However, this study used two sampling methods (*snowball* (or network) sampling and *purposive* sampling) simultaneously to recruit individuals who are living with HIV/AIDS to participate in the study. Snowball sampling is a way of recruiting participants who met the recruitment criteria through recommendations by other participants with similar criteria (Bryman, 2012).

3.2.5.1 Study Context: Nigeria

According to the National Agency for the Control of AIDS (2015, p.1), Nigeria lies within:

> *'latitudes 4^0 1' and 13^0 9' North and longitudes 2^0 2' and 14^0 East and is bordered by four countries: The Niger Republic to the North, Republic of Chad and Cameroun to*

the East, the Republic of Benin to the West and to the South by the Atlantic Ocean' (NACA, 2015).

Nigeria has an overall surface area of about 923,768 square kilometres and 800km of coastal area (NACA, 2015). Nigeria is the most populated nation in Africa with about 178 million people having over 250 ethnic groups, with Yoruba, Igbo, and Hausa as the main ethnic groups (Williams, 2016). It has over 500 indigenous languages, with English serving as the official language (NACA, 2015). It also has 36 states divided into six geographical zones including the Federal Capital Territory (FCT) in Abuja. It is called 'The Giant of Africa' (Awofala and Ogundele, 2016; Williams, 2016).

Oyo state

Oyo state is one of the 36 states of the Federal Republic of Nigeria formed in 1976 from the Western State including the Osun State, which later split in 1991. According to Encyclopaedia Britannica (2007), it is popularly referred to as the Pace Setter. It has an area of approximately 28,454 square kilometres and is ranked 14th by size in Nigeria. The state gently rises from about 500 meters in the southern part to about 1,219 metres above sea level in the north. It consists of 33 local government areas. It is ethnically homogenous, being mainly inhabited by the Yoruba ethnic group located in the South-West geopolitical zone of Nigeria. Farming is the main occupation of the people in the State (Amole, Olaolorun & Odeigah, 2013). One of the towns in Oyo state is Ogbomoso.

Ogbomoso

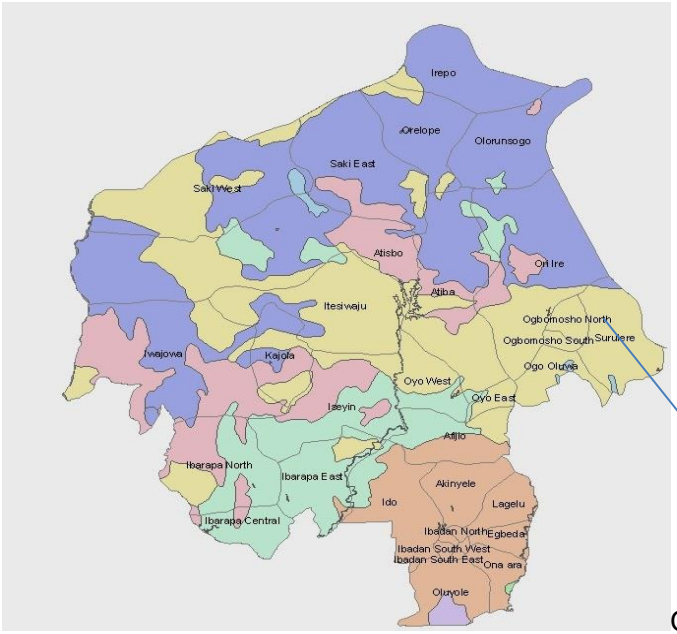
Figure 8: Map of Oyo state, Nigeria showing Ogbomoso City (Encyclopaedia)

According to Amole, Olaolorun & Odeigah (2013), Ogbomosho (also Ogbomọṣo) is located about 100km north of Ibadan, the capital of Oyo state (Amole *et al.,* 2015). It is one of the cities in Oyo state, south-western Nigeria, on the A1 highway (Willams, 2016). It was founded in the mid-17th century and has a population of approximately 801,389 (Amole *et al.,* 2015). The majority of the population are members of the Yoruba ethnic group (Williams, 2016). It is one of Nigeria's largest urban centres with several hospitals and primary health centres that attract Nigerians from around the country (Amole, Olaolorun & Odeigah, 2013).

3.2.5.2 The Selected Hospital (SH)

For ethical reasons, the hospital will be given a pseudo name called the Selected Hospital (SH). It is one of the first-class Christian Mission Teaching Hospitals established by American missionaries and known for excellence with trained health professionals (Amole *et al.,* 2015). It was originally established as a medical facility and recently transformed into a teaching hospital. It has more than 300-beds capacity with over 400 staff and medical students, multidisciplinary facilities, residency programme and nursing and midwifery accredited courses (Amole *et al.,* 2015). Over 50,000 outpatients and 10,000 inpatients are registered.

Figure 9: Map of Oyo state showing all local government



Ogbomoso North where the hospital is located

The reason for selecting this hospital is outlined in section 3.2.5.3. In this hospital, a huge number of people with HIV receive treatment from across the country because of their history of providing good services for HIV patients. More details of the criteria for choosing the hospitals for the study are detailed in *Hospital eligibility criteria*.

3.2.5.3 Eligibility Criteria

Hospital eligibility criteria

For the purpose of this study, a hospital or clinic is where people access treatment and other medical services are rendered. The eligibility criteria for the hospital are:

- Providing health care services for HIV/AIDS at primary, secondary and tertiary levels.
- Must have an ethics committee for research, so that any ethical issues can be reviewed.
- Providing a comprehensive HIV care programme such as Voluntary Counselling and Testing (VCT) services, Prevention of Mother to Child Transmission (PMTCT), Antiretroviral Therapy (ART) for adults and children, support group services and treatment of opportunistic infections.

- The arrangement of necessary support for participants during the interview process, if required.

Participants' recruitment

As this study is exploring HIV disclosure among people living with HIV in the workplace, the sampling targeted major categories of employment. These include unskilled, low skilled, skilled and professional workers, gender, and their length of diagnosis with HIV. A purposive sampling of five (n=5) participants was initially planned to be recruited in each category with the total number of 20 participants, who meet the eligibility criteria as stated in Table 3 below. However, due to the challenges of recruiting employed people during the work days, the researcher focused on recruiting all interested participants that were eligible regardless of their categories of employment. Although the sampling may not be representative in terms of size, it provided essential elements in demographic data gathered from different participants from different working environments.

Table 3: Participants' inclusion criteria

Inclusion Criteria

1. Age: Between 18 and 65 years
2. Nationality: A Nigerian adult
3. Diagnosis length: Living with HIV/AIDS for more than 6 months
4. Treatment: Currently registered or receiving HIV/AIDS treatment from any of the eligible Oyo state recruitment centres/hospitals
5. Occupation: Currently employed or left employment within the last 6 months
6. Mental ability: Possessing the cognitive ability to participate

All the patients who did not meet the above criteria were excluded.

The WHO (2015) reported 15-45 years as the most at-risk HIV population, the recruitment age for this research was between 18 years and 60 years. The reason for this age selection is that,

in Nigeria, 18 years is categorised as an adult and an individual would be expected to have completed the basic formal education up to secondary school level. While some people opt out of continued higher education, some go for 'job hunting' and others may combine working and schooling. Henry, *et al.* (2015) reported a similar study using age 18 and above as a criterion for recruiting the participants. In addition, age 60 was used as the age limit for recruiting an eligible participant. In Nigeria, 60 years of age is the retirement age or 30 years of service. It was also stated that participants must be living with HIV for more than 6 months. This is because participants are more likely to have more information to share about their experience of living with HIV and taking a decision to disclose or not to someone. This criterion was also consistent with a similar study (Henry *et al.,* 2015) investigating HIV disclosure experience of PLWHA in countries like Congo, Ecuador, Republic of Congo, Mali, Morocco, and Romania.

3.2.5.4 Recruitment procedures

For this study, selection criteria were used to strategically select participants that are relevant to the research question. It is a deliberate way of selecting particular units of a study population for producing a sample that represents the study population. A stratified random sampling was initially planned to obtain a representative sample. These strata are based on age, gender and work category, but these categories were not major criteria for selection due to limited time, resources, and limitations to accessing the potential participants. Other adjustments are discussed in the *pilot section*.

In this study, the researcher was flexible in recruiting any eligible participants. Eligible participants in this study were all selected with three important features in common: they were employed Nigerians and HIV- seropositive for more than six months as this played out in their disclosure experience in the workplace. Efforts were made to have an equal representation of all work categories. The researcher recruited a variety of participants and members of the resulting sample differ from each other in key characteristics relevant to the research question. More details of recruitment procedures are discussed in section 3.2.5.4.

This type of sampling is called a non-probability sampling. This type of sampling selects participants based on the subjective judgment of the researcher rather than a random selection of participants (Seale, 2012). Also, the researcher's aim is in-depth, idiographic understanding of the data rather than a generalizable data. This justifies the phenomenological stance of this study which focused on the depth and richness of the data rather than statistical representation. HIV/AIDS remains a stigmatised condition in Nigeria and recruiting a representative sample for a face-to-face interview may not only not be feasible in terms of the resources but may not provide the in-depth account of each participant (Bowling, 2009). Therefore, purposive sampling was used as a type of non-probability sampling. Detail of a non-probability purposive sampling is found in section *3.2.5 Population, sample and sampling tool*. The selection of participants in a purposive sampling is based on the researcher's knowledge and credibility.

In this study, the researcher recruited participants who had the potential to answer the research question using the eligibility criteria discussed in section *3.2.5.3 Eligibility Criteria*. As previously mentioned, the snowball technique was also used to find participants for the study through a recommendation from the eligible participants (Bowling, 2009). Saturation was reached after interviewing 18 participants, but the last two participants were also interviewed as the interview date had already been booked. According to Marshall et al. (2013), saturation is reached when additional participants no longer provide any additional information but may result in data replication or redundancy. Saturation then largely dictates the number of participants needed in qualitative research in ensuring a credible analysis and reporting (Marshall et al., 2013). Creswell (2013) proposed that saturation is usually reached with 12 participants. However, Marshall et al. (2013) recommended fifteen participants as a minimum for most qualitative interviews when participants are homogeneous. Homogeneous means participants recruited have similar elements. However, where participants are heterogeneous, each category of participants may need to reach a saturation which may produce a larger number of participants. For instance, research investigating the impact of a newly introduced

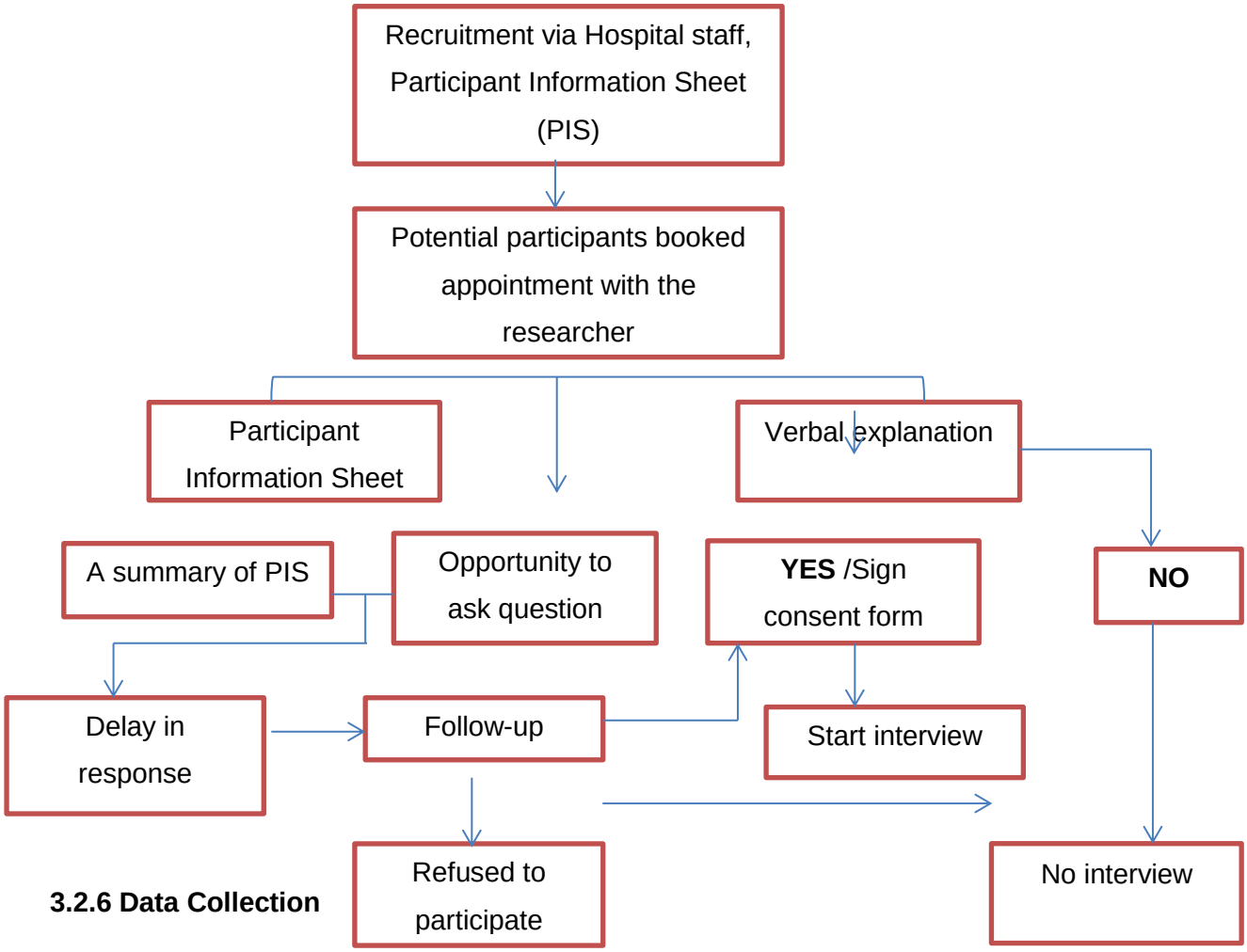
health intervention which aimed to recruit service users, clinicians and the members of a community should recruit each category of participants separately and allow each to separately reach saturation.

The hospital was contacted via phone call and a meeting was arranged with the Unit Head, the doctor in charge and the patients' leader, in advance of the researcher visits. With the help of the staff, the purpose of the study was explained to patients in the waiting room. Patients interested in the study who met the eligibility criteria were recruited in this way. See Appendix 1 for further explanation of the purpose of the study and a participant information sheet (PIS) given to participants. Patients who agreed to the research and who met the eligibility criteria were recruited, and a consent form was signed before conducting the interview. Bowling (2009) established a need to keep participants informed about the aim of the study via a covering letter containing information, and how this helps to clarify any concerns participants may have before a decision is made to be involved in the study. Each eligible participant was asked to recommend other potential participants. The detail on snowball sampling is discussed in section 3.2.5 of this chapter. Subsequently, a PIS with the researcher's contact details was passed on to the eligible participants through the hospital staff.

Participants were given the time to read the information about the research and ask questions before they decide to take part in this research. It should be noted that the time taken to make a decision with regards to participating varies: some participants showed instant interest to participate after the purpose of the research was explained to them, and the consent form was signed, while some took days to give a response. However, the interview dates were agreed for each participant to respond. The time interval between when the PIS was sent out and when responses were received was between a few hours and weeks. Subsequently, interviews were arranged based on the date, time and venue for the interview. If satisfied, contact details were requested from the participants and the researcher's contact details were provided on the participant information sheet. Not all potential participants that were approached participated as involvement in the research was voluntary. However, the number

in this category was difficult to record as hospitals and unit heads/staff spoke to the individuals that might be eligible, and only the few that agreed to be involved were presented to the researcher. Figure 10 shows the recruitment process of participants in this study.

Figure 10: Recruitment Procedure



3.2.6 Data Collection

Interviewing is a research tool for gathering information; it is highly flexible but can also be an unpredictable form of a social research tool. Qualitative studies move the researcher's experience into a series of representations of participants' experience and draw conclusions about the research topic (Lu & Gatua, 2014). The quality of an interview depends on the context, participants' experience, and the demographic information about the participants. These include gender, social class and the cultural orientation of the participants. Interviewing assumes an epistemological position that 'social world is assumed to have an existence that is dependent on the language used to describe it' *(Byrne, 2012, p. 211)*.

Qualitative interviewing is a way of exploring people's attitudes and values which may not be obtained through the use of observation or questionnaire. One of the reasons why qualitative interviewing is used in this study among people living with HIV/AIDS is that it is a suitable method to investigate complex issues and provides a way interviewees respond with their voices using their own languages (Byrne, 2012). It is also a method that provides a flexible way of asking questions, especially when researching among 'hard to reach' groups or researching sensitive topics: the use of an open-ended question builds rapport which then leads to the topic of interest. However, this could raise ethical (*See 3.2.8 ethical consideration section*), methodological and epistemological issues in the way information is gathered (Bryman, 2012). The epistemological issues focus on the information the interviewee tells and what they do not tell, and how interview data are assessed and analysed (Byrne, 2012). This issue can be dealt with in the way the interviews are viewed: either as data collection or data degeneration. When interviews are seen to provide facts about the social world, the interview will be treated as a *resource*. However, when the main focus is on how an event is described to gather a particular effect, the interview is seen as a *topic* (Byrne, 2012). This interview is treated more like a *resource.*

Interviewing can be done either face-to-face or by telephone (Silverman, 2013). Unlike telephone interviews, face-to-face gives an opportunity for the researcher to explain complex questions and observe the use of non-verbal communication to probe further. The use of visual aids is possible, and the settings controlled in other ways, and participants are able to elaborate the answers given (Byrne, 2012). It is generally thought that people prefer to speak to a sympathetic and a good listener than filling out a questionnaire for an invisible researcher. The use of interviews is reported to be more flexible than the use of a questionnaire as it produces in-depth information for sensitive research and provides different meanings within a context (Byrne, 2012). As this research is sensitive research among a 'hard to reach' group, the interview was used as an appropriate tool for data collection. This is to get participants' first-hand experience of their perception of HIV/AIDS disclosure in the workplace.

3.2.6.1 Interview Schedule

As phenomenological research uses unstructured or semi-structured methods of data collection (Gray, 2013), a semi-structured interview schedule was used during the data collection as a tool to interview PLWHA who were employed. A copy of the interview schedule is found in Appendix 2a. The justification for using this tool is that it elicits information and a wider conversation that can often generate interesting results (Charlton, Lapthorn and Moncrieff, 2014). This interview schedule was translated from its original form (English) into the language that most participants speak (Yoruba) and employed verbatim as a style of transcription. The interview conducted in the local dialect was translated into English by the researcher and proof-read by a bilingual translator to ensure accuracy following the advice of Regmi, Naidoo & Pilkington (2010). These issues were addressed in more detail in section 3.2.7.1 Data transcribing. A semi-structured interview produces some form of structure that a researcher follows, but questions may not necessarily follow a specific order (Byrne, 2012). This gives a semi-structured interview schedule flexibility and allows for open-ended inquiry (Bryman, 2012). In addition, questions that were not included in the interview schedule were asked as the interview progressed.

In-depth interviewing requires a skilled interviewer who is fully aware of the aims of the study and has the ability to engage the participants in a discussion about their feelings, experience, behaviour, and attitudes (Charlton, Lapthorn and Moncrieff, 2014). The researcher used a semi-structured interview guide to ask a series of questions that cover a wide range of instances and vary in the sequence of how the questions were being asked.

3.2.6.2 Interview schedule

The questions in the interview schedule were adopted from reviewing some related studies that investigated disclosure in the workplace in the US, Zambia and in South Africa (Fesko, 2001; Musumali, 2012; Peters, 2011). The process of modification was followed by consultations and getting feedback from the Nigerians in the UK (eight participants) via Skype call to identify potential problem/s with the interview questions and to identify words or phrases

that may seem inappropriate. The interview skills were developed by practising the interview with a Nigerian in the UK similar in culture and geographical location as with potential participants for developing interview and analytic skills, and also to get feedback. The final process of modification was conducting a pilot study with four participants meeting all criteria as with the main study participants. See more details of the pilot study in section 3.2.9.

Building a rapport with the potential participants before an interview can promote smooth communications between the researcher and the participant, which can also contribute to the robustness of the data. Wagstaff & Williams (2014) stated that engagement before an interview does not only contribute to the richness of the data, it enables the participant to feel more confident with the researcher in connection with sharing information that is considered to be sensitive or private. Similarly, building a rapport with a wide range of people is one essential quality of a good interviewer (Bowling, 2009). The researcher was trained in the attributes of a good interviewer as established before the start of data collection procedures by the supervisory team, and also attended a discipline-specific programme designed for PhD students in health studies by the University.

Trust was built gradually at the recruitment stage where the purpose of the study was explained clearly, and the choice of involvement was also explicit through the use of the participants' information sheet. The process of questioning was also not rigid; participants were asked in different ways and the first few minutes of the interview were aimed at building a good rapport with the participants. This left the participants happy at the end of the interview.

In addition, the researcher ensured that participants were listened to, carefully without unnecessary interruption, and used a simple language. This makes the participants feel they are the 'expert' when sharing their life experiences. During the interview, participants were made to feel that they owned their experience and that this could be communicated in their own way. The researcher was committed not to approve or disapprove any statement made

by the respondents but to be *neutral.* This is to limit the bias of the researcher influencing the response.

Participants were given full attention without the researcher giving any form of distraction. This is one of the reasons why the interview was auto-taped. The audio recording was essential in this study as it made it easier for the interviewer to give full concentration to the interviewee during the interview process. The consent form was obtained from each participant before they were audio recorded. The consent form also contained information about the interview being recorded and signatures were requested prior to the start of the interview. Questions about audio recording were asked by participants based on what it will be used for, its importance, how and where to store the data (*see more details in section 3.2.8*) and answers were provided. During the interview, questions were asked in a clear voice and were presented in a simple and straightforward language. This is also very important for obtaining an accurate recording.

Finally, the researcher also ensured commitment and perseverance as these attributes were most useful during the recruitment process. As this study focuses on recruiting employed PLWHA, the researcher was committed to following-up potential participants to include them in the study.

3.2.6.3 Reflexivity

Reflexivity is best carried out throughout the research process as the way to explore the biases brought by the researcher to the study such as relevant expertise, experience and preferences (Rivas, 2012). Reflective sensibility helps the researcher to draw out the methodological problems at a certain stage of the research. *Reflexivity* is important for a researcher in the process of data collection. In this study, reflective reporting with the use of field notes was used to report on each interview and lessons learned. The type of information collected when researching people's lived experience must contain holistic information using written reports or tape (Murray & Chamberlain, 1999). Anything that can be used to reflect on activities carried

out to give useful information is recommended to contribute to robust data. The use of field notes was adopted to assist in analysing the data not included in the transcript (Byrne, 2012). Field notes were written on how the interview went, lessons learned and how the next interview could be improved and other general observations. Each day of the interview, a report was written on how the interview went, the participant's reaction and interaction with the researcher, any change(s) compared to previous interviews, things that did not go well and things that went well. The field notes were used to monitor the progress of the study, enhance the process of data collection, and adjust methods if needed. It could also serve as a means of justifying how the interview was conducted (Byrne, 2012).

3.2.7 Qualitative data analysis

3.2.7.1 Data transcribing

The use of language is important in most qualitative research (Inhetveen, 2012); it plays a fundamental role as an instrument of power to construct meaning which originates from various cultures (Claramonte, 2016). Translating some interviews from the original language (Yoruba) into English was not an easy task.

'Language is rich and evolving, and words may be used in an unconventional way' (Rivas, 2012, p. 372).

Translation involves knowledge of different approaches and skills to deal with the language used in data collection (Regmi, Naidoo & Pilkington, 2010). It is like a 'boundary crossing' between the two languages. There is an increasing trend in the translation of a 'source language' other than English in health and social research (Regmi, Naidoo & Pilkington, 2010). This is important to understand human behaviour and social processes in natural settings. Research can be cross-cultural when a study is conducted within a culture different from that of the researcher or uses an instrument that was translated from its original source.

Transcribing the information verbatim is one of the challenging stages of data analysis (Braun and Clarke, 2013). It involves the step by step way of understanding the general idea within

the transcripts, then extracting codes (or sub-codes) and developing themes that explain the perception of participants on HIV disclosure in the workplace. However, it is an important process in phenomenological research wanting to explore the lived experience of a participant's world. This style transcribed not only spoken words but other sounds in the recorded data, which aims to include what was said and how it was said in the transcript (Braun and Clarke, 2013).

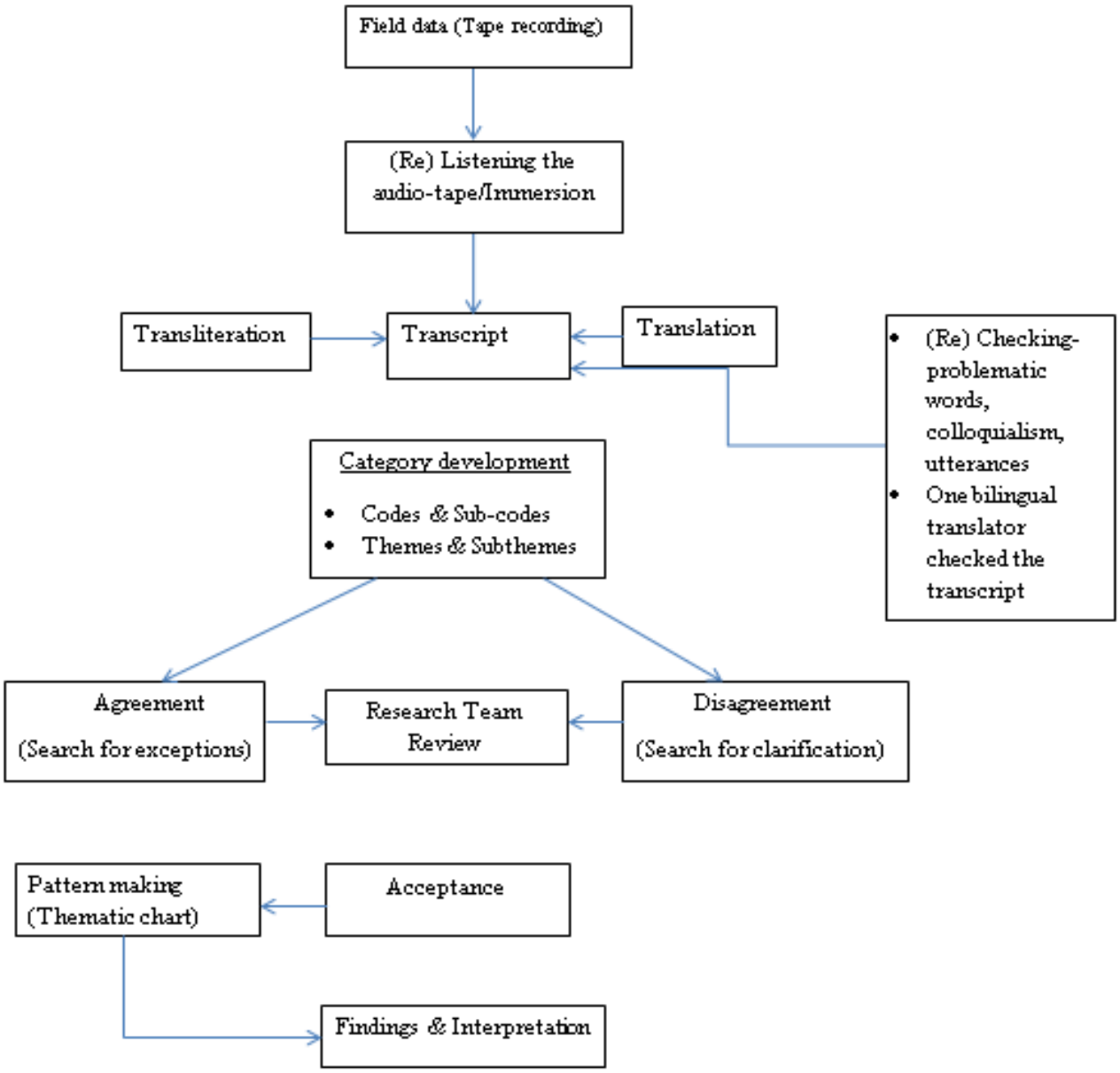
The literature emphasis on the role of the researcher or that of the translator/interpreter is often ignored, and the method of translation of data in most published literature has not been prominent in the discussion (Inhetveen, 2012). This could make it difficult to evaluate the rigour of the study at the same time, in a way culturally sensitive to the population of interest. However, there is a growing interest in submitting articles for publication from researchers of non-English speaking countries to gain a wider audience of readers worldwide. An interview is one of the key techniques in gathering information in qualitative research (Inhetveen, 2012). Transforming the information from one language to another is rooted within the sociocultural context and the decision made during the process of analysis influences its interpretation (Regmi, Naidoo & Pilkington, 2010).

The translation may not be straightforward and is open to interpretation, but it opens up possibilities of new ideas (Inhetveen, 2012; Claramonte, 2016). In this study, HIV infection as a stigmatised condition among the participants was expressed in a certain collective language that the researcher who does not come from a similar background may not understand. For example, many participants avoid naming HIV when sharing their experience. However, it is expressed as *'this thing'*. This expression will not always be understood unless the researcher understands how the expression presents itself to make the participant feel comfortable about talking about the condition. Another example is '*I have stopped thinking'*. The meaning of *thinking* is equivalent to '*I have stopped worrying about the infection'*. Hence, this statement was interpreted in relation to sociocultural meaning and not the direct English meaning. Inhetveen (2012) said literal translations are valid in certain circumstance. However, the

researcher can be at a risk of distorting its meaning due to sociocultural differences in the use of lexically corresponding concepts. This explains the context of cross-cultural translation. For example, a participant was explaining how people reacted when they heard she was HIV-positive, and she said, '*that is their cup of tea',* which may not make sense within this context unless it is replaced by another word that gave the same meaning. When a participant says, '*that is their cup of tea'* in Nigeria, it means, '*that is their issue'*. Although the researcher understands what the participant means, the researcher required that the participant confirm its interpretation. Regmi, Naidoo & Pilkington (2010) said that concept, idea, and feelings are not always the same from one language to the other.

It is a challenging task to represent participants' view when using interpretative approaches (Inhetveen, 2012; Hendrickson *et al.,* 2013; Xia, 2016), particularly when analysing and synthesising data into a different language. To deal with this, the concept of culture is needed to make a meaningful, valid and accurate interpretation. Shortcuts such as omitting words, the use of abbreviation and excluding what researchers may call 'irrelevant information, noise or rhythms may misrepresent the information, affect the analysis and cause ethical issues (Claramonte, 2016). The process of translation and transliteration is time-consuming and resource intensive (Hendrickson *et al*., 2013), and in this study, the process of translation and transliteration took more than two months to complete. Although, some authors (Hendrickson *et al*., 2013; Regmi, Naidoo & Pilkington, 2010) suggest the use of a different person to translate the data to avoid the researcher being overwhelmed, in this instance, the translation was done by the researcher with the use of one bilingual translator to double check the transcript for accuracy as shown in Fig 11 (adapted and amended from Regmi, Naidoo & Pilkington, (2010).

Figure 11: Data Translation, Transliteration, and Analysis



Adapted and amended from Regmi, Naidoo & Pilkington, (2010)

3.2.7.2 Coding

A qualitative researcher aims for a thorough and high-quality transcript although this may not be termed 'accurate' due to a debate on what constitutes an accurate transcript. Usually, a good transcript or 'good enough' transcript is achievable (Byrne, 2012). Therefore, in this study, after transcribing the data, information was analysed using Braun and Clarke's model of analysis and interpretation. Immersion in data is first done by reading and re-reading the data a number of times before the coding process. This builds the foundation of meaning and helps in making sense of the data (Rivas, 2012). Coding in qualitative data analysis is a way by which data moves from quality into a quantity that helps patterns to be identified in data analysis (Byrne, 2012). In this study, coding is done by reading line by line, or sentence by sentence to identify codes and themes. Inductive and deductive coding are used in this study. The researcher has the idea of what is being looked for deductively and inductively, coding to explore this in detail. This researcher is using an inductive approach and aims to allow the data to 'speak for itself' (Rivas, 2012).

When coding began, data were broken down into small fragments (codes) and were disconnected from the whole transcripts. A memo was also created during the analysis. A memo is a personal informal note that is not prepared to be given to an audience but is written to keep a record of ideas that came through during analysis, progress difficulties and surprises within the analysis. Potential emergent codes were noted and patterns within the codes were identified. These patterns are called themes and gather ideas, thoughts or feelings throughout the text (Smith, 2009). The researcher also tries to record the initial codes by writing codes in the margin close to the relevant data transcript (see appendix 2b for a sample of a coded transcript). Coding is thus a way of grouping similar data together which have consequences on the meaning generated. A researcher codes in a particular way to show how the world is seen which can be narrow (a restricted way of gathering thoughts), or creative (producing new insights) (Byrne, 2012).

Thematic analysis treats the interview as a *resource.* The researcher is involved in the decision-making process of identifying and selecting data that are more relevant (Byrne, 2012). This practice also involves identifying patterns in the data and categorising them into similar groups (Creswell, 2013). Thematic coding was used to code data in this study. Rivas (2012) said thematic coding is used when trying to make sense of the data by grouping into themes or patterns. It is systematic and moves from the description of individual experience to looking across the data set. However, content analysis is different from the thematic analysis as it focuses on the frequency at which words or small bits of data appear (Rivas, 2012). Other analytical approaches that can be used to develop patterns and themes are discourse analysis and narrative analysis, which needs some technical and theoretical understanding and may not be easy to use by a novice researcher (Creswell, 2013).

Ethical issues may arise at the stage of data analysis which could reflect how knowledge is produced (Byrne, 2012). At this stage, what needs to be decided comes out of the final report and this may silence some voices while others are used. To limit this bias, the researcher analysed and coded all transcripts, and codes were categorised into themes and sub-themes. See Appendix 3 for a sample of a coded transcript and the themes that were developed. As codes were gathered, there was more refining of codes and more categories were developed. The early analysis informs the subsequent ones and gaps in the data were filled as the analysis progressed and new and unexpected themes were identified. The stage where no new themes emerged is called *saturation of themes* (Rivas, 2012).

Although Nvivo 10 software was initially employed, it was not used as it involves a rigid way of analysing data and increases the pressure to concentrate more on 'volume and breadth rather than on depth and meaning' (John & Johnson, 2000). This software is designed to analyse small or large volumes of data (Bergin, 2011). Rivas (2012), suggests the use of software may not be the best option with the inductive approach as the initial codes have the tendency to change and these changes may be difficult to effect with the use of the software.

After the manual coding process, the codes were grouped into preliminary categories, and then themes were formulated

Categorising codes is an important process in the data analysis as it moves analysis from description to a more detailed explanation and identification of new ideas for the research problem (Byrne, 2012). This helps to manage the codes and spot new emerging interpretation of data. After categorisation, the data is operationalised to turn the abstract ideas into meaningful ideas. Constant comparison of codes is done to ensure that similar codes are under the same category and helps to avoid being overwhelmed with data. After the categorisation, themes were generated. During the data analysis, negative instances were also identified. This is an idea that came out of the data that contradicts the rest of the data and these also were accounted for. A summary table of codes for all the participants was drawn to synthesise and integrate themes. Details of these are found in Appendix 2c.

Member validation is a way of checking, commenting and assessing the accuracy of the themes by the participants (Bryman, 2012). Rivas (2012) said care must be taken in relying on participant assessment as they may not be the right person to judge the 'accuracy' of the theme. In this study, the researcher gave a brief summary of the interview for the interviewee and asked if what was presented was correct and made amendments when needed. In addition, the coding process was discussed with the supervisory team who commented on the content and modified the coding as a team.

3.2.8 Pilot Study

A pilot study was carried out as a final stage in designing an interview schedule. It is sometimes called a feasibility study which accesses important concepts that are needed in the main study (Wray, 2015). Pilot studies can be carried out among a small proportion of the participants before the start of the actual research (Phellas, Bloch & Seale, 2012). Testing questions on a similar group that would be included in the actual study were recommended to access the research instruments, understand some of the challenges ahead, the resource

needed, and also for training purposes, especially for a new qualitative interviewer (Wray, 2015). Recognising challenges during a pilot study gave an overview of what to expect during the main data collection and gave the researcher an opportunity to analyse the challenges and deal with them before the start of the main data collection (Bryman, 2012).

The main aim of the pilot study was to access the data collection tool (interview schedule). The pilot was undertaken between September and October 2015 and employed people living with HIV/AIDS were recruited. An interview schedule with audiotape was used to collect data. A reflective/field note was used to account for the overall processes and reflective practices.

Objectives

The pilot study was conducted with the following objectives:

(a) Assess recruitment strategy, method, and procedures
(b) Test the appropriateness, sequence, and sensitivity of the data collection tools
(c) Training opportunity for the researcher

The participants have similar characteristics of inclusion as participants included in the main study except that they were recruited in a different location (also a hospital) from the hospital used in the main study. The hospital used for the pilot study is a government-owned hospital (Hospital A) and for the main study is a private hospital (Hospital B). The difference between the two hospitals does not have any significant effect on the selection as they were all assessed through a similar process of recruitment using similar inclusion criteria.

Byrne (2012) noted that a successful interview requires skills. The skills are developed before the start of the data collection by practising interviews with a colleague and the study supervisor with the aim of getting feedback on the method of asking questions, attitudes, building rapport, acting professionally, showing flexibility and the willingness to listen to the participant. See the details of this in section *3.2.6.2 Interview schedule.* Feedback was acted upon. Further training was also gained through online courses and workshops on developing

an interviewing skill. The process of piloting also involved seeking assistance from eight University of Bedfordshire colleagues that have a similar culture to the participants to give feedback on the structure and the sensitivity of the questions. All of these contributed immensely to gaining confidence in interviewing participants living with HIV/AIDS in Nigeria.

3.2.8.1 Lessons learned from the pilot study

The lessons learned from the pilot study can be categorised into three main themes as detailed in Appendix 7:

(a) Recruitment, access, procedures, and retention

(b) Appropriateness of data collection tools (semi-structured interview schedule)

(c) Personal development and training

Recruitment strategy

As the purpose of the research is to explore the perception of HIV disclosure in the workplace among people living with HIV/AIDS, one of the main criteria is to recruit employed people living with the condition. An employed individual also must be working under a person, organisation or any institution and not be self-employed. The recruitment was a major challenge in recruiting many of the registered patients as some had their own private business, were older people or they had not had a job within the previous 6 months.

Similarly, potential participants preferred to come on appointment days, which get busy because it is a day when doctors assess HIV patients for treatment. Because of this, unit staff found it difficult combining research recruitment and getting patients to see the doctor. This challenge was mainly experienced in Hospital A (OSH) and contributed to the low response rate.

In Hospital A, a few people were eligible, and the logistical support was poor. At the time of the study, the hospital was having a renovation that took more than two weeks. They were not willing to give any room for an interview except an open waiting reception that was filled up

with other patients. There was no room or private place in the hospital and the participants were not given the decision to choose the interview venue of their choice as the hospital did not agree to the arrangement. It was also difficult to get participants during weekdays.

Appointment days posed another problem. The appointment days vary and are usually once or twice a month. This means the researcher may not get to meet some participants. In some cases, the interview was mostly interrupted if doctors needed to attend to patients despite the arrangement made to avoid this.

Interviews were limited to the hospital premises in an open waiting reception that was filled up with other patients. This affected the recruitment plan as the researcher was limited to the only room available that did not provide privacy for participants. The unit staff preferred talking to their patient personally before I approached them, and any interested potential participants were directed to the researcher. This required some adjustment to the recruitment strategy by having a group discussion with the unit staff and their support leaders on the purpose of the research and who to recruit.

In Hospital B, a counsellor's office was given at first which made some participants feel uncomfortable. The counsellor came in and out of the interview room and privacy was compromised. The researcher negotiated another room which gave more privacy but could still be occupied on busy appointment days.

These challenges affected the recruitment process in government-run Hospital A, and as a result of these logistical challenges, Hospital A could not be used for the actual study. Four participants were eventually interviewed for the pilot study while participants recruited from the private hospital called Hospital B presented fewer challenges.

Procedure

The participants were given an information sheet about the research (Appendix 1). Most interviews took place at the hospital premises within the HIV treatment unit in Ogbomoso. All

four participants agreed immediately to participate after understanding the purpose of the research and signing the consent form (see Appendix 4). Efforts were made to build a good rapport before the start of the interview. As noted, the use of semi-structured interview was important in this study because HIV is a sensitive and personal issue and it was important to the researcher for participants to give an account of their perception from their point of view. Hence, the one central question put to all participants was: *How would you describe your experience of living with HIV in your workplace?*

Young participants were asked about their education level which is something central to the life of every young Nigerian. However, the majority of the respondents were over 40 years old and were more comfortable discussing their work lives. Some happened to be interviewed at their workplace since they were working in the same hospital but were not necessarily working in the HIV Treatment Unit. Each participant was encouraged to speak to the tape recording and be free to share their experience.

3.2.8.2 Adjustment to Interview Schedule

The semi-structured interview format gave the participants an opportunity to express their own views, experiences, and feelings on HIV/AIDS disclosure and most importantly their perception of disclosure in the workplace. It was also an avenue for the researcher to probe for more information for clarity, simplify statements and questions made by the participants. Although it was a semi-structured questioning, possible follow-up questions were based on the literature review and points made from previous interviews. Participants were able to take their time in answering questions without feeling pressured by the timescale: the average duration was 45 minutes. This helped to understand how long each interview will take when collecting data for the main study. Details of their demographic information gathered prior to the interview exercise gave the researcher the ability to relate well with the participants. This was also included during the main study. The demographic information includes their age, partnership status, the level of education, type of occupation and length of diagnosis.

Phellas, Bloch & Seale (2012) argue that participants used in the pilot phase need to be excluded from the actual study to avoid inaccurate answers. Here, the participants used for the pilot study were excluded from the main study. The use of a pilot study before the start of the main study assisted the researcher to restructure the interview questions, identify the expected challenges, develop a refined recruitment strategy to increase the response rate, and the average time duration used for the individual interview. The pilot study also helped to address ambiguous and sensitive questions in the interview schedules. For example, to ask how a participant contacted HIV may sound sensitive but asking about how it is to live with HIV may create a discussion on their experience of living with HIV/AIDS and issues regarding their perception on HIV disclosure in the workplace.

3.2.9 Ethical Considerations

There has been increased emphasis on the ethical aspects of social research for decades which has fuelled considerable debates regarding research practices (Seale, 2012). Ethics is a form of professional practice which is centred on the procedural issues (Ali & Kelly, 2012). There are principles that are common: they are not rules but are generally used in social research for the development of ethical guidelines when conducting research (Beauchamp and Childress, 2009). These principles will be discussed briefly, and include *Beneficence, Non-Maleficence, Autonomy, and Justice*.

Beneficence is the moral duty of the researcher to provide balanced benefit against risks, and an act of kindness when conducting a research (Jahn, 2011) while Non-Maleficence is the duty of a researcher to avoid causing harm to the participants (Beauchamp and Childress, 2009). However, this may be difficult to predict in some cases as research could cause distress and has a degree of impact on the participants when participating in the research (Ali & Kelly, 2012). In incorporating the two principles (Beneficence & Non-Maleficence) in this study, the researcher tried to limit distress with the use of eight colleagues prior to data collection. These are culturally related to the participants and can identify questions that may make the participants be distressed. The research team also assessed the questions, and then a pilot

study was conducted before the start of the main study. For instance, a question was asked about how distressing it was when participants were diagnosed with HIV, however, the question was identified by the team as one that can make them feel distressed. The researcher then reflected on the pilot study to effect some changes in the final draft of the interview schedule. The contact details of the support group or sources of counselling were made available before the start of the interview.

Autonomy is the obligation of a researcher to respect the decision-making capacity of participants able to give consent without interference by the interviewer (Ali & Kelly, 2012; Jahn, 2011). This principle is discussed more extensively in section 3.2.8.3 *Informed consent.* Justice is maintained when there is balanced fairness in the distribution of benefit, risk, cost, and resources (Beauchamp and Childress, 2009). This principle is not always applicable to social research but may possibly be seen in medical research in the area of physical response to treatment (Ali & Kelly, 2012). In social research, harms and benefits may be difficult to predict and hence there is difficulty in balancing against the risks. However, there is a moral obligation by an individual concerning risks to the wellbeing of the participants, and of others who may be involved or affected by the research (Beauchamp and Childress, 2009).

To maintain the professional integrity of the researcher, the relationship with the participants before, during and after the data collection should be constantly reflected upon (Ali & Kelly, 2012). Hence, the importance of reflectivity as discussed in *Section 3.2.6.3.* This section focuses on the researcher's relationship with the participants and the issues of hierarchy in this study.

3.2.9.1 Differences in power

In recent decades, research ethics have been shifted to the role of power difference at all stages of the research including the dissemination of the result (Ali & Kelly, 2012). Power difference may arise between the researcher and the participants when conducting research. In many cases, the researcher is seen to control the process of a qualitative research and may

be seen as ‘all-powerful’ (Creswell, 2013). Due to this awareness, the way in which the data is collected may be impacted, especially when conducting a focus group, for example, when grouping both the managers and the workers together. This could have an impact on the data and of course, the participation and the relationship long after the researcher has left the study site. When in this type of situation, the participants may lose trust and confidence in the process of the research and, therefore, this may affect the response rate and participation (Ali & Kelly, 2012).

In this study, the power differences focussed on the social differences between the participants and the researcher, including gender and age. However, this was counteracted by building rapport with the participants including the use of other attributes of an interviewer as discussed in section *3.2.6.2 Interview schedule.* Seale (2012) recognises that a researcher must be characterised by trust and integrity. However, poor ethical practices increase the chance of harm and prevent future research being taken among this population in the future. During the interview, the participants were given time to express emotions. The researcher acknowledged the importance of safety of the participants. For example, if the participant felt very distressed, the interview would be terminated, or re-arranged. It is important that the researcher thinks of what happens to their participants after they have left especially when conducting a face-to-face interview. With this in mind, arrangements for support were made by the hospital management before, during and after the interview. The support included access to counselling services when participants felt distressed as a result of participating in the research.

Nigerians often show support to students, and there is respect of such for Nigerians who have travelled to developed countries like the United Kingdom. The researcher introducing herself as a PhD candidate at one of the UK’s universities invited a level of ‘respect’ and ‘recognition’ towards the researcher, although that created the role of an outsider. In addition, participants also believed the information given would provide more understanding of the experience of

employed people living with HIV/AIDS and could give necessary support to policymakers and others alike.

According to Seale (2012), the issue of power differences may become an important ethical practice when the researcher has to conduct research among people who are different in class, race, ethnicity, and gender. This type of power difference may redefine the role of the researcher as an insider or outsider. In this study, participants are different from the researcher in terms of gender (for male participants) and HIV/AIDS status. These differences made the role of a researcher an outsider. However, the researcher is similar to the participants in term of cultural understanding of the societal norm, nationality and in some cases, gender (for female participants). The researcher could therefore also be called an insider. There has been a growing debate among educational, sociological and qualitative researchers about the ways in which the identity of the researchers can influence the research process, analysis and findings (Kerstetter, 2012). It is often known that research studying identity usually perceives identity as a singular and fixed construct (Gunter, Thomsona and Gunterb, 2011). However, identity could be multiple constructs where a researcher is identified as both an insider and outsider. A reflective detail of how the identity (insider/outsider role) is played out during the recruitment and interview period is discussed in section *3.2.10*, of this thesis.

Within the ethical practice of power differences, there are also other ethical considerations with the participants. These are privacy and confidentiality and gaining informed consent.

3.2.9.2 Privacy

Privacy refers to confidentiality and data protection (Ali & Kelly, 2012), and is very much linked to the idea of informed consent (Bryman, 2012). Invasion of privacy may not be completely guaranteed in most research studies, as it can be as simple as stopping someone along the street to fill a survey. Invasion of privacy is not only viewed as harm in itself but could be subjecting an individual to the possibility of harm, by depriving an individual of certain protection privacy offers (Ali & Kelly, 2012). Disclosing someone's personal information could

result in visible or invisible harms and the researcher has the responsibility to protect the privacy of the participants. These include: using a private room for an interview without any form of distraction and ensuring that the purpose of the study was explained, especially what the information will be used for.

During this study, potential participants were asked if they would be interested to participate in the research by the duty staff. The staff on duty had been initially briefed about the purpose of the study and the ethical procedures for recruitment. If participants were interested in the research, their names were put together and the researcher was given the opportunity to meet with them. Recalling that research among PLWHA is sensitive (Poudel, Newlands & Simkhada, 2016), the majority of the potential participants were seen by the researcher in a private separate room given by the hospital. This private separate room was used to meet with the potential participants to explain further the purpose of the study and to conduct the interviews. Although, two participants were interviewed outside of the hospital as they were unable to come to the hospital on weekdays: one participant was interviewed in his private home while the other in a home of one of the hospital staff. For privacy, interview venues were chosen to take into account the safety of both the participant and the researcher, which also ensured confidentiality.

In contrast to the *UK, Nigeria does not have clear data protection legislation (Udoma & Belo-Osagie, 2015).* There is also not any federal or state legislation that protects personal data as they have in other developing countries like South Africa, and India, except the Draft Guidelines on data protection provided by the National Information Technology Developing Agency *(Udoma & Belo-Osagie, 2015).* Therefore, the researcher used the UK's 1998 Data Protection Act as a guiding set of principles to follow in storing personal data (Data Protection, 2015). The data protection covers both the facts and the opinions expressed by people. The eight principles are: data should be fairly and lawfully processed, it should be processed for limited purposes, it should be data relevant and not in excess, data must be accurate, kept for a particular period of time, data should also be processed according to the data subject's

rights, it should be stored in a secure place and not transferred to countries without adequate protection. All these were important for this study.

Care was taken to protect the data collected and this was done throughout the stages of the research. This did not only protect the participants but the organisation that gave approval for conducting the research among the participants. Storing data in a secure medium promotes confidentiality (Ali & Kelly, 2012). Hence the data was stored in an encrypted device kept in a secured cabinet and could not be accessed by anyone except the researcher. Participants were assured that their information would be safely kept in an encrypted device and could only be accessed by the researcher, or if necessary, by the academic supervisory team. The data will be destroyed when it has served its purpose. In the process of protecting the identity of the participants, a code or number was given to each participant and was written on each transcript. Each participant was given (or could suggest themselves) a pseudonym, or could opt for an interview ID number, for example, 001, 002, 003. After the interview, all identifying information about the participants was destroyed. Seale (2012) argued that it is not always possible to ensure confidentiality, and the researcher should make it clear where this will not be possible, and therefore informed consent sought.

3.2.9.3 Informed consent

Informed consent has been seen, for many years, as an important element of research ethics both in natural or social science, where the participant has the right to know what is happening to them (Ali & Kelly, 2012). Obtaining informed consent supports the principle of individual autonomy, and it is universally accepted as a way to protect the right of any participant participating in research (Bryman, 2013). The purpose is for the potential participants to decide what their best interest is and to understand the risk involved.

In order for the consent to be informed, participants in this study were given the purpose of the study, the eligibility criteria for participation, and the potential risks and harm that may be experienced using concise, detailed and simple language for easy understanding. Information

about the study was given to each participant verbally and through a written sheet called a Participants Information Sheet (PIS). See appendix 1 for a sample of the PIS. Coercion or misleading the participants about the purpose of the study was avoided by engaging with the unit staff on the purpose of the study, the eligibility criteria and the rights of the participants so that when informing the participants at the first stage of recruitment, misleading information and coercing them could be avoided.

Informed consent should always be obtained from the participants whenever possible as this could be verbal but written is more ideal (Ali & Kelly, 2012). In this study, written informed consent was obtained from each participant. While it is important to note the mental capacity of each participant, all were mentally able and could individually give independent consent without any support. This was confirmed by the unit staff. Participants recruited were all employed adults. A copy of the agreement was signed by each participant making the decision to participate. See Appendix 4 for a sample of informed consent. To make the interview easier, a good rapport was built with the potential participants.

3.2.9.4 Compensation

The majority of the participants were compensated with less than $5 and/or a light refreshment after completion of taking part in the interview. This compensation was provided to cover transportation costs for participants who took part in the research, although some had their interview conducted while waiting to see the doctor. No compensation was given to the staff.

3.2.9.5 Ethical issues

Ethical issues may arise where there is pressure from all sides to present findings in a particular way. This can happen when research is funded or come from other members of the research team (Seale, 2012). It is not the case in this study as the researcher is not funded by any organisation but acts as the sole owner of the project.

Maintaining confidentiality in this research may not be guaranteed as the quotations will be used. Therefore, the researcher is protected by gaining consent before the start of data collection. This shows the importance of gaining informed consent. Also, the researcher asked the potential participants if they would be interested in the findings of the study as copies will be made available to the hospital used. The researcher excluded any demographic data from the transcript that could serve as an identification of any participants. This is also because HIV research has strong ethical and human rights implications (Poudel, Newlands & Simkhada, 2016).

With the expansion of social research and the need for research in society, ethical guidelines were set up with review bodies to ensure ethical research was conducted according to the guidelines previously discussed (Ali & Kelly, 2012). See *section 3.2.6.2* for more details. In the researcher's institution, the ethical review committee was set up to scrutinise the research protocol, and to give helpful advice. Ethics Approvals were granted by the Nigerian Ministry of Health (MOH), the selected private hospital, Oyo State Hospital (SOH) and the Institute for Health Research (See Appendix 5a, b & c). The condition to undergo ethical review, in recent times, has involved the legal requirement such that the universities use insurance companies to protect their researchers against harm (Ali & Kelly, 2012). In this study, the public indemnity insurance of the University of Bedfordshire was obtained before the start of data collection that insured both the researcher and the participants (See Appendix 6).

3.2.10 The insider-outsider role of a researcher

The practice of reflexivity requires the researcher to recognise their positioning and use that to address some blind spots that affect bias or trustworthiness in qualitative research (Gunter, Thomsona and Gunterb, 2011). This is why it is important to reflect on the insider/outsider positions of a researcher (Hayfield and Huxley, 2014). Meanwhile, the position of a researcher may change based on where and when the research is conducted, the personality of the researcher and the topic under investigation (Kerstetter, 2012).

There are discussions around the role of a qualitative researcher among the study population and the role of an insider or outsider. Whether a researcher is an outsider or an insider, researchers and their relationship with the participants has an impact on the meaning that is co-created between them (Hayfield and Huxley, 2014). This explains the role of the identity of the researcher within the community in which they study (Kerstetter, 2012). Gender, class, and ethnicity are some of the elements to understand the role and the identity of researchers to the participants (Dwyer & Buckle, 2009; Crean, 2018). According to the literature (Gunter, Thomsona and Gunterb, 2011), that explains the insider/outsider role. Insiders possess a substantial knowledge of what is happening inside of the study population. However, an outsider has limited information about the study group under investigation.

The familiarity as an advantage of being an insider helps in developing and designing interview questions and gives easy access to participants during data collection (Hayfield and Huxley, 2014). Insiders are more aware of their potential participants and the design of research ethics in bringing the representation of voices of participants to the research (Hayfield and Huxley, 2014). While the research conducted by the insider may be richer due to shared identity or familiarity, assumptions may be made regarding the actual experience of a participant. Also, during the data analysis, there is a risk of overlooking some important content that could explain an individual experience (Hayfield and Huxley, 2014).

The aforementioned shows that there is no certainty that an insider will understand participants' perspectives more than an outsider, especially if there are other factors that differentiate them such as social, economic and environmental factors. For instance, if a researcher who is HIV/AIDS positive is studying the lives of PLWHA, although they may have a similar condition and their survival experience may be similar, other factors such as the type of work they do may have an influence on the way their stories are shared. Studies (Moore, 2015; Breen, 2007; Dwyer & Buckle, 2009; Crean, 2018) have also revealed how the position of an outsider might be advantageous to research. An outsider approaches the study site

naively and strangely, but their curiosity helps to seek more knowledge about the study population (Gunter, Thomsona and Gunterb, 2011).

My position as a researcher

I carried out the data collection in a place where I grew up and, in the hospital, where I was born. I was familiar with the study environment including the town and the hospital used for data collection. One of the elements that made me feel like an insider was that I understood the local dialect, Yoruba, and I can speak and write it at an advanced level. This town was where I lived and schooled the most part of my life. However, I felt like an outsider when carrying out this research because I have been away from the town for the last 6 years in the UK mainly for further study. Also, I have never worked in this hospital and have never had the opportunity to meet any of the hospital patients. I do not know how the hospital works neither do I know the management of the hospital or the HIV unit. So, I could say I am an insider-outsider. But carrying out my research in this town and the hospital that is known to me does not exactly make it a completely new and strange environment to me. I became an insider researcher when I first decided to conduct research among the Nigerian population and in fact in a place where I lived as a child. However, I consider myself primarily as an outsider because of my position as a “researcher” and “academic” and most importantly, when I was asked by one of the participants whether I am HIV-positive or not, and since I am not, the position of an outsider became pronounced.

What it means by living with HIV/AIDS in my town

Before reporting on my role within the insider/outsider perspective, contextualising this reflection within the research topic will provide an understanding of the study environment that was used in carrying out the research.

My town has a population that is mostly religious (Amole, Olaolorun & Odeigah, 2013). The two most recognised religions are Christianity and Islam. They have a common ground in their beliefs, just like the majority of Nigerians, that HIV/AIDS is a deadly disease and people get

infected as a result of infidelity and immorality (Awofala and Ogundele, 2016). This makes it more stigmatised and remains a condition that the majority living with HIV/AIDS would rather keep secret than to disclose. Conducting research in one of the hospitals in the town could not have been possible without a well-planned recruitment strategy. Although I lived in the town for the most part of my life, I have not worked in the hospital before neither have I carried out research among HIV patients. An extensive literature in the introduction and literature review chapters has explained in detail the stigma-related issues among the Nigerian population on HIV/AIDS

Revealing insider/outsider role to participants

In qualitative research, it is important for a researcher to consider how they are seen by their participants as this could influence the willingness of participants to participate and interact well to the study (Hayfield and Huxley, 2014). If this sort of information is not provided, participants may create an assumption of who the researcher is. For instance, participants may assume researchers who study HIV patients are also HIV positive or have some sort of relationship with HIV patients. To avoid this, I provided explicit information about myself to participants both in the participants' information sheet and before the start of the interview. During the interview, I made it clear I am not living with HIV/AIDS, but I was open to learning from my participants. Also, I made it known that I have never been employed in any job related to HIV and I have been away for a few years to study in the UK, but I knew someone who was lost to HIV when it was difficult to access HIV treatment. Meanwhile, understanding the local dialect and conducting the research in the town where I grew up provided a space to build a quick rapport with the participants. As I declared my role as a researcher and the purpose of the study, I found that it encouraged openness and trust between me and the participants. It also built rapport during the interview, which is vital during data collection (Hayfield and Huxley, 2014). There is also the ability to generate rich data and to be in a strong position to make sense of the data.

During the interview, participants used local slang that I understood and that made the conversation more cordial and the data richer. Details of these are found in section 3.2.7.1 *Data transcribing* of this thesis. I also came across to them as an expert, which sometimes made some participants assume that I had the capability to provide some specialist advice or offer certain support for them. For others, they perceived I could talk to the government directly to implement a policy that would better their lives. Despite these assumptions, my role was continually emphasised to the participants as a researcher and not a clinician or a policymaker. Hayfield and Huxley (2014) said because of these assumptions, certain responsibilities may be placed on an insider researcher where participants feel the researcher would have some knowledge on how to manage their situations.

Meanwhile, my role as an outsider has also given me the opportunity to have an open mind into understanding the day-to-day struggles of employees living with HIV/AIDS. Since I have not conducted any HIV-related research and I do not have the condition, I was able to listen and learn from an individual's story, and also able to ask questions or probe for deeper understanding of the perception of disclosure of an employed person living with HIV/AIDS. Some authors (Moore, 2015; Breen, 2007; Crean, 2018) argue that outsiders are in a position to see what an insider is not able to see. This could be true because going into the interview with an open mind reduces the chances of making an assumption on behalf of a participant. An outsider may ask some naïve questions which participants expect, however, participants may assume that an insider is knowledgeable and therefore may not bother to give a richer explanation of the situation. Given my outsider role as a UK student and one who is not HIV positive, I was keen to understand whether participants felt comfortable discussing their lives during the interviews in an informal post-interview. I found out that participants enjoyed talking to me as they felt they were the 'expert' and were in a position to make me understand their lives as someone living with HIV/AIDS and their perception of HIV disclosure in the workplace.

Combining both roles during the data collection had contributed to the response rate of participants and also gave richer and deeper data. In reflecting on my role as an

insider/outsider simultaneously, I concluded that I am different from my participants but still similar to them. It is therefore important for researchers to reflect on what position and identities they hold and reveal their level of involvement with, and their detachment from, the research.

3.2.11 Summary

Phase two of the study outlines the methods used in conducting the second aim of the study. It further discusses the justification for the research design and how data is collected, in this case, gathering information from the chosen participants through the semi-structured face-to-face interview. The fundamental principles of ethics and other ethical guidelines related to social research have been discussed. The method of data analysis, thematic analysis, is discussed as a means of analysing data by immersing oneself in the data, developing code and generating themes. A pilot study was conducted to assess the methodology of the research, and lessons learned about recruitment strategy, procedures and personal training and development to improve the interview schedule and recruitment strategy for the main study. Finally, ethical considerations pertaining to this research were discussed, and the role of the researcher as an insider-outsider during the data collection was reflected upon.

The next chapter is the findings chapter.

Chapter Four: Findings

4.0 Overview

As previously mentioned, this thesis involves two phases: the systematic review and qualitative research. This chapter will present the findings from both phases. In the first phase,

the systematic review findings are presented using meta-analysis. A total of fourteen (n=14) studies were included in this phase although 10 studies were available for publication in April 2015[3]. The information collected is presented in various categories, such as characteristics of the studies, outcomes of disclosure, and factors associated with HIV (non)disclosure and its impacts, then contextualising the findings based on their methodological strength. Themes are developed across all included studies. These themes explain HIV disclosure among people living with HIV, its pattern, and its outcome. The findings from this systematic review show that disclosing one's HIV seropositive status, mostly to sexual partners, is an important aspect of the lives of people infected with HIV/AIDS, and could result either in positive or negative outcomes, or both. A significant number of people disclosed to their sexual partners, some to the rest of their families and friends, few to their religious leaders, work colleagues or employers. There is currently limited research focusing on workplace disclosure among people living with HIV/AIDS in Nigeria and there is no research, to the best of the researcher's knowledge that has adopted a qualitative approach to investigating disclosure in the workplace.

The systematic review phase addresses the first aim of this research: collect and synthesise evidence from studies on HIV/AIDS disclosure among people living with HIV/AIDS in Nigeria. Its objectives are to understand the factors that may influence the disclosure of HIV status and its impact on people living with HIV/AIDS, and also to describe the prevalence and patterns of disclosure, outcomes, and factors associated with HIV disclosure in Nigeria

The second phase focuses on the gap identified in the first phase. In phase one, studies retrieved found that information about HIV disclosure is limited in the workplace and that no study on HIV disclosure among employed PLWHA has adopted a qualitative approach. It is important to explore HIV disclosure in the workplace using a qualitative approach because it will give a richer and more in-depth understanding of the perception of HIV disclosure in the

[3] See appendix 13 for the publication abstract of the systematic review study and a link to the article: https://www.ncbi.nlm.nih.gov/pubmed/27059370

workplace among employed PLWHA in Nigeria. The second phase then explores HIV disclosure among PLWHA using a semi-structured interview schedule as a means of data collection. The second phase of this study focuses on exploring the perception of HIV disclosure in the workplace among people living with HIV-positive status in Nigeria. All interviews were transcribed and analysed using thematic analysis. The extracts from these narratives were presented in the form of themes which aimed to explore objectives 2, 3, & 4 of this study.

Applying the two phases of this study explores the perception of PLWHA on HIV disclosure in the workplace in Nigeria.

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Phase one: Systematic review findings

4.1 Introduction

This section presents the findings of the systematic review which is to collect and synthesise evidence from existing literature on HIV/AIDS disclosure in Nigeria using developed inclusion criteria. Meta-analysis was used to analyse the ten included articles. The findings from the

systematic review will inform the second phase of this study (primary qualitative study). This systematic review was conducted between January 2015 and September 2017.

4.1.1 The Electronic Databases

The initial search resulted in 2480 titles of which 2289 were excluded based on title and abstract. 191 articles were retrieved (n=191) as shown in Table 4 below. The duplicated copies were removed (n=32). The titles and abstracts (n=159) were screened. One hundred and twenty-five (n=125) articles were excluded. The full texts of thirty-four (n=34) were retrieved against the inclusion criteria. A further twenty (n=20) articles were excluded because they did not address HIV disclosure among HIV positive individuals in Nigeria (n=5); their full text could not be retrieved (even after emailing the corresponding authors) (n=4); reported on domestic violence only (n=6); investigated how caregivers disclosed HIV status to children (n=4) and one study used secondary data for its investigation.

Figure 12: the flowchart showing the selection process

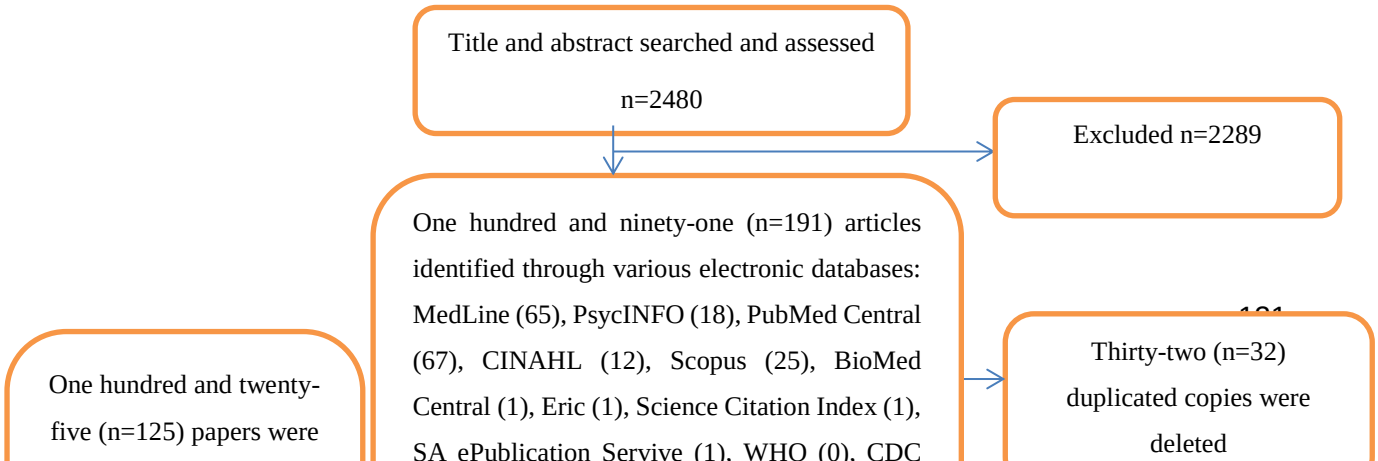


Table 4: Number of relevant papers per database

Database	Number of papers
CINAHL	12
PubMed Central	67

PsycINFO	18
MedLine	65
Scopus	25
ERIC	1
BioMed Central	1
Science Citation Index	1
SA ePublications Service	1
Total	**191**

4.1.2 Characteristics of studies

The majority of the included studies (n=13) used quantitative cross-sectional research design (Amoran, 2012; Salami *et al*., 2011; Olagbuji *et al*., 2011; Ezegwui *et al*., 2009; Sagay *et al*., 2006; Sadoh & Sadoh, 2009, Dankoli *et al*., 2014; Okareh *et al*., 2013; Adebayo *et al*., 2014; Titilope *et al*., 2011; Ogoina *et al*., 2015; Adebiyi & Ajuwon, 2015; Adekanle *et al*., 2015), and provided estimates of disclosure and information on the strategies PLWHA used for disclosure while one study used a longitudinal research design (Ujah, Ezechi & Ohihoin, 2015) among pregnant women living with HIV/AIDS and attending HIV treatment clinics over a 9-year period.

Table 5: Characteristics of studies on HIV disclosure, Jan. 1986-September 2017

Author(s)/year of publication	Region	Study design	Sample size	Gender of participants

Amoran (2012)	Ogun State, South- West	A cross-sectional study (Quantitative)	637	M & F
Salami, *et al*. (2011)	Ilorin, Kwara State, Middle Belt	A cross-sectional study (Quantitative)	253	M & F
Olagbuji (2011)	Benin City, Edo State, Southern Nigeria	A cross-sectional study (Quantitative)	166	F (pregnant women)
Ezegwui, *et al*. (2009)	Enugu, Enugu State, South-East	A cross-sectional study (Quantitative)	92	F (pregnant women)
Sagay, *et al*. (2006)	Jos, Plateau state, Middle Belt	A cross-sectional study (Quantitative)	570	F (nursing mothers)
Sadoh and Sadoh (2009)	Benin City, Edo state, south-south	A cross-sectional study (Quantitative)	62	F (nursing mothers)
Dankoli, *et al*. (2014)	Gombe, Gombe State. North-East	A cross-sectional study (Quantitative)	198	M & F
Okareh, *et al*. (2013)	Oyo state, South-west	A cross-sectional study (quantitative)	57	F (married women)
Adebayo, *et al*. (2014)	Ondo State, South- West	A cross-sectional study (Quantitative)	578	M & F
Titilope, *et al*. (2011)	Lagos state, South- West	A cross-sectional study (Quantitative)	499	M &F
Ogoina, *et al*. (2015)	Okolobiri, Bayelsa state, South-South	A cross-sectional study (Quantitative)	123	M&F
Adebiyi & Ajuwon (2015)	Ibadan, Oyo state, South-west	A cross-sectional study (Quantitative)	392	M&F
Adekanle, *et al*. (2015)	Osogbo, Osun state, South-west	A cross-sectional study (Quantitative)	122	F (married women)
Ujah, Ezechi & Ohihoin (2015)	Lagos, Lagos state, South-west	A longitudinal study (Quantitative)	4435	F (pregnant women)
Table key: F-female; M – male				

The studies vary in their sample size, sample strategies and methods of data collection (see Table 5). A considerable number of participants were sampled among married women, pregnant women or nursing mothers registered for Prevention of Mother-To-Child

Transmission (PMTCT) (Olagbuji *et al*., 2011; Ezegwui *et al*., 2009; Sagay *et al*., 2006; Sadoh & Sadoh, 2009; Okareh *et al*., 2013; Adekanle *et al*., 2015; Ujah, Ezechi & Ohihoin, 2015) while other studies sampled both male and female (Amoran, 2012; Salami *et al*., 2011; Dankoli *et al*., 2014; Adebayo *et al*., 2014; Titilope *et al*., 2011; Ogoina *et al*., 2015; Adebiyi & Ajuwon, 2015) of which four studies (Adekanle *et al*., 2015; Ujah, Ezechi & Ohihoin, 2015 Ogoina *et al*., 2015; Adebiyi & Ajuwon, 2015) were published after this systematic review was published.

The main themes across all included studies were developed first by extracting the ideas across the studies and then grouping these ideas into main ideas called the themes. The main themes across all included studies are discussed below.

4.1.3 Prevalence and Pattern of Disclosure

HIV disclosure made mostly depends on the level of intimacy with the recipients of an infected person (Ezegwui *et al*., 2009), and the type of relationships such as sexual partners or spouses (Adebayo *et al*., 2014; Titilope *et al*., 2011; Amoran, 2012; Ujah, Ezechi & Ohihoin, 2015; Ogoina *et al*., 2015; Adebiyi & Ajuwon, 2015) and family members (Adekanle et. al., 2015); non-family members were the least preferred choice (Dankoli *et al*., 2014). The included studies reported 50.9% disclosure rate among sexual partners (Amoran, 2012), 39.5% among adult patients (Salami *et al*., 2015); 88% women attending antenatal clinics (Olagbuji *et al*., 2011); 96.7% pregnant women (Ezegwui *et al*., 2009); 89% nursing mothers (Sagay *et al*., 2006); 91.4% nursing mothers (Sadoh & Sadoh, 2009); 97.5% adult patients (Dankoli *et al*., 2014); 75.6% sexual partners (Adebayo *et al*., 2014); 61.5% among adult patients (Titilope *et al*., 2011); 83.7% sexual partners (Ujah, Ezechi & Ohihoin, 2015); (Ogoina *et al*., 2015); sexual partners 50.7% (Adebiyi & Ajuwon, 2015). See Appendix 8 for a description of the study findings on the prevalence of disclosure, outcomes, and factors associated with disclosure.

Only one study (Ogoina *et al*., 2015) did not give information about the rate of disclosure. However, the rate of disclosure reported in most studies was based on self-reports which may

not be reliable (Yonah, Fredrick & Leyna, 2014). A number of included studies (Salami *et al*., 2011; Ezegwui *et al*., 2009; Sagay *et al*., 2006; Titilope *et al*., 2011) rely on the self-report, although two (Olagbuji *et al*., 2011; Ujah, Ezechi & Ohihoin, 2015) established disclosure by telling participants to bring in their partners for confirmation before they were included in the study. HIV disclosure was also extended to families, relatives, and friends. Meanwhile, a few studies reported disclosure to in-laws, religious leaders (pastor, priest, or imam) or work colleagues. Overall findings showed that the majority of the participants reported voluntary or self-disclosure to at least someone while three studies (Sagay *et al*., 2006; Okareh *et al*., 2013; Adekanle *et al*., 2015) reported assisted disclosure with the help of healthcare professionals. These healthcare professionals include doctors, nurses or healthcare assistants who assist patients to discuss HIV treatment and management with a close member of the patient's family.

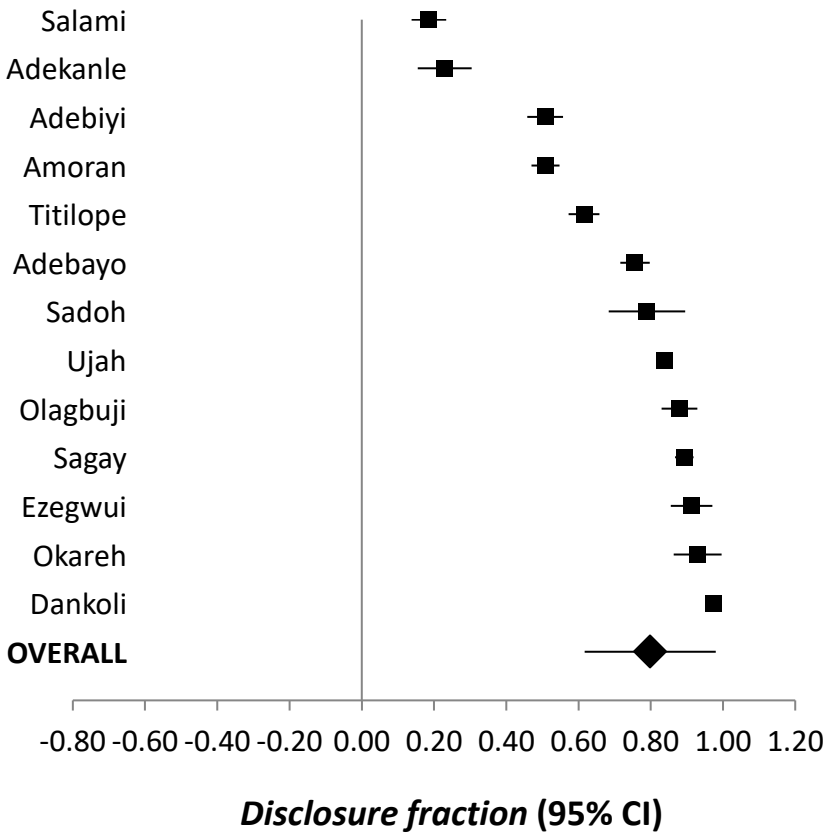
A meta-analysis on the disclosure rates to sexual partners was performed as a significant number of studies reported the disclosure rates to sexual partners. The heterogeneity estimated (I^2) was 0.0%, which indicates that most of the observed variance was spurious (Borenstein *et al*., 2009; Higgins *et al*., 2003). Following our publication (Adeoye-Agboola *et al.,* 2016) on HIV disclosure among people living with HIV/AIDS in Nigeria, four further papers were identified and analysed to assess any differences from the published systematic review. Among the four studies, one study (Ogoina *et al*., 2015) did not report the rate of disclosure. After conducting a meta-analysis, the rate of disclosure of participants who have got HIV is between 64-100%.

According to the meta-analysis[5], 84% of the people disclosed their HIV positive status to their partners. Between 64-100% is a large interval and that suggests that this study was not homogenous. The heterogeneity test showed no heterogeneity because some studies have 20% disclosure and some 90%. The reason for the differences is because of the differences

[5] The meta-analysis table showing rate of disclosure is found in Appendix 10

in the sampling size/population. A Forest plot of the proportion of disclosure, including 95% confidence intervals is shown in Figure 13.

Figure 13: Forest plot for the disclosure rate from partners



4.1.4 The Outcomes of Disclosure

All studies (Olagbuji *et al*., 2011; Ezegwui *et al*., 2009; Sagay *et al*., 2006; Sadoh & Sadoh, 2009; Okareh *et al*., 2013; Adekanle *et al*., 2015; Amoran, 2012; Salami *et al*., 2011; Dankoli, *et al*., 2014; Titilope *et al*., 2011; Ogoina *et al*., 2015; Adebiyi & Ajuwon, 2015) but two of the included studies (Adebayo *et al*., 2014; Ujah, Ezechi & Ohihoin, 2015) reported outcomes on perceived reaction (either positive, negative or both) of the recipient following the disclosure. Results showed that following disclosure, a large number of respondents received support from their partners (86.9%), 5.7% were indifferent, 6.7% were quarrelsome and abusive and 1% was violent (Sagay *et al*., 2006). Notably, over time, more became quarrelsome (20.9%) (Ogoina *et al*., 2015; Okareh *et al*., 2013); and some reported violence (Sagay *et al*., 2006). A study (Sadoh & Sadoh, 2009) reported stigma/discrimination, the accusation of infidelity,

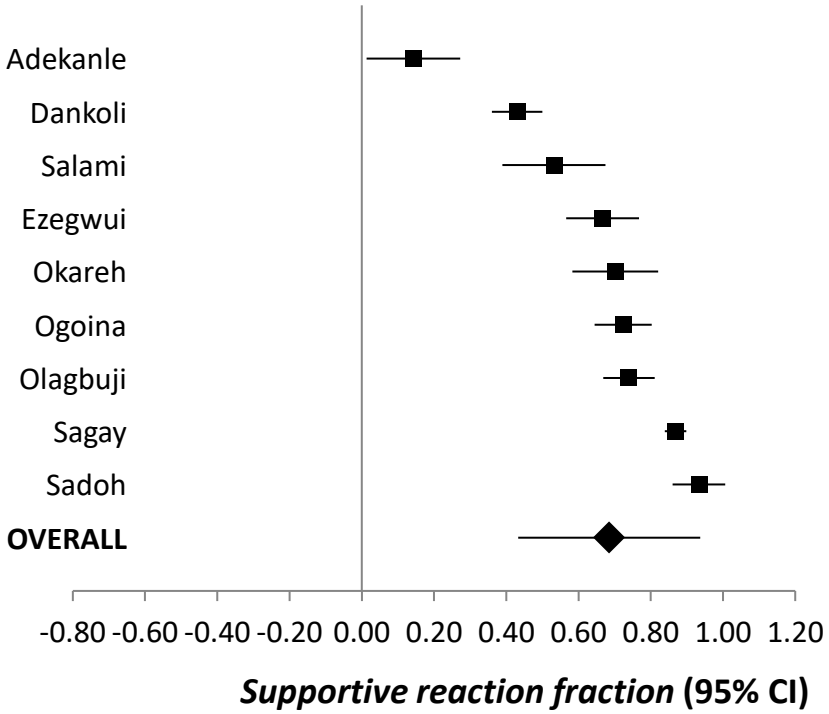
divorce and abandonment as results of the disclosure. A study (Olagbuji *et al*., 2011) that involved 166 pregnant women receiving antiretroviral treatment found that the majority felt that disclosure earned them support from their partners (74%), where a few described their partners as indifferent or abusive at 6.8% and 19.2% respectively.

In a study (Ezegwui *et al*., 2009) involving 92 pregnant women with HIV/AIDS, the majority of the participants (96.7%) disclosed their status; however, the outcomes reported were both positive and negative. On the positive aspect, disclosure brought financial support, kindness, and spiritual support especially from the members of the family. However, it caused stigma (37.1%), blame (23.6%), rejection by family (18.0%), abandonment and violence/assault (7.9%). Among 70.2% of married women receiving support after disclosure, 29.3% experienced quarrels/abuse (Okareh *et al*., 2013). A similar study (Adekanle *et al*., 2015) reported sex deprivation by partners after disclosure is made, and not wanting to consider condom use.

A meta-analysis[6] of 'supportive responses to disclosure of HIV seropositive status' was performed for nine articles, with five articles (Amoran, 2012; Adebayo *et al*., 2014; Titilope *et al*., 2011; Adebiyi & Ajuwon, 2015; Ujah, Ezechi & Ohihoin, 2015) either not mentioning the effect of disclosure, or only reporting the rate of no adverse reaction. In this heterogeneity analysis, I^2 was 0.0%, which indicated that most of the observed variance was spurious (Borenstein *et al*., 2009; Higgins *et al*., 2003). After adding the two new articles that also reported the supportive reaction of disclosure, there is no difference in the first and the second analysis as they both found a similar result. The supported reaction was 77%, overall, which is quite a large variation. Overall, people who disclosed to their partners got a favourable response but there was substantial variability between studies because of factors such as the difference in their sample size. A Forest plot of the proportion of disclosure, including 95% confidence intervals is shown in Figure 14.

[6] The meta-analysis table showing supportive responses is found in Appendix 10

Figure 14: Forest plot for the presence of a supportive reaction from partners



4.1.5 Factors associated with HIV disclosure

The studies revealed some factors which are associated with disclosure such as gender, the period since diagnosis, family and marital status, awareness of partner's status, education and socio-economic status.

4.1.5.1 Gender difference

A study (Salami *et al*., 2011) reported gender influence on disclosure where women were found to disclose more than men with p= 0.001. However, some studies reported no significant relationship between gender and disclosure (Amoran, 2012; Titilope *et al*., 2011). One study (Dankoli *et al*., 2014) also found that HIV patients prefer to disclose to female rather than male relatives. Women were more likely to know about their HIV positive status earlier than men as HIV testing remains part of the pregnancy antenatal routine (Olagbuji, 2011; Ujah, Ezechi & Ohihoin, 2015).

4.1.5.2 Period since diagnosis

The length of time since diagnosis was also reported among six studies (Amoran, 2012; Salami *et al*., 2011; Ezegwui *et al*., 2009; Sagay *et al*., 2006; Dankoli *et al*., 2014; Okareh *et al*., 2013) to be affecting disclosure; it ranges from the day of diagnosis to 3 years after being positively tested for HIV. A study (Sagay *et al.,* 2006) from Northern Nigeria found that mostly all (89%) respondents have disclosed and, of these, a substantial percentage of PLWHA (28%) waited more than 6 months to tell their partners, and another 24.5% waited for more than a year. Another study (Amoran, 2012) found that disclosure was made as early as the day they received their test results while it took some people months before they could relate their information to their sexual partners, where: 17.3% disclosed on the day of receiving the test result, 15.5% in two weeks, 9.7% between 2 and 4 weeks, 8.3% in more than a month. Similarly, a study (Sagay *et al*., 2006) that investigated partners' disclosure among mothers receiving treatment found that the decision to disclose their HIV positive status increased over time after 12 months of diagnosis.

4.1.5.3 Family and marital status

Some of the factors that influenced disclosure had to do with family type, marriage type or marital status, as these vary greatly. It was reported that disclosure rate is higher in the monogamous family than polygamy (Amoran, 2012; Salami *et al*., 2011), and the affected member in the monogamous family experienced more positive outcomes than the corresponding member in polygamous homes. Also, married women disclosed 12 times more than single women (Titilope *et al*., 2011).

4.1.5.4 Awareness of partner's status

An awareness of the partners' status increased the chances of disclosure in some studies, with an increase in disclosure found among HIV-seropositive couples while this was generally lower in negative partners and casual relationships (Ezegwui *et al*., 2009; Ujah, Ezechi & Ohihoin, 2015). Three studies (Amoran, 2012; Salami *et al*., 2011; Sagay *et al*., 2006) identified knowledge of the recipient's status as a key factor in disclosure. In a study (Amoran,

2012) sampling 637 HIV-positive patients accessing HIV support, respondents without the knowledge of their partners' status are significantly less likely to disclose (p=0.00). Similarly, while investigating status disclosure among 253 PLWHA, it was found that patients' knowledge of their sexual partner's status was significantly more correlated with disclosure given p=0.02 (Salami *et al*., 2011). HIV disclosure is more likely in a seroconcordant relationship than a serodiscordant relationship (Ujah, Ezechi & Ohihoin, 2015).

4.1.5.5 Education and socio-economic status

Some studies reported the level of education as one of the factors that can influence disclosure (Amoran, 2012; Ezegwui *et al*., 2009; Dankoli *et al*., 2014; Titilope *et al*., 2011; Ujah, Ezechi & Ohihoin, 2015). For example, research conducted in the Ogun state in Nigeria found that the higher the level of education, the higher the rate of disclosure (Amoran, 2012). However, a report from North-Eastern Nigeria found that a low level of education is associated with disclosure (Okareh *et al*., 2013). Financial support also appeared to play a major role in disclosure. In Benin City-Nigeria, mothers who adopted a 'no breastfeeding' choice needed to disclose to their partners to gain financial support. Hence, the decision to disclose varies depending on the situation in which an infected person finds him/herself, and the kind of support expected from the receiver of the information.

4.1.6 Psychological and emotional impact

Six studies (Amoran, 2012; Sagay *et al*., 2006; Sadoh & Sadoh, 2009; Okareh *et al*., 2013; Adekanle *et al*., 2015; Ogoina *et al.,* 2015) reported the psychological and emotional impact of disclosure experienced by PLWHA. A study (Amoran, 2012) highlighted the fear of separation/abandonment (37.7%), fear of being negatively labelled (5.0%), being isolated by partners (25.5%), physical abuse (9.2%), and other reasons (4.2%). Another study reported pressure from family, fear of stigmatisation, fear of divorce, the accusation of infidelity as factors affecting the psychological and emotional state of health of PLWHA. The above influenced the respondents' ability to make decisions in terms of disclosure of their seropositive status (Sadoh & Sadoh, 2009; Okareh *et al*., 2013).

4.1.7 Factors associated with non-disclosure

In terms of the major findings around the prevalence and factors associated with nondisclosure, only five studies (Olagbuji *et al*., 2011; Sagay *et al*., 2006; Sadoh & Sadoh, 2009; Titilope *et al*., 2011; Adebiyi & Ajuwon, 2015) provided a full report, eight studies (Salami *et al*., 2011; Olagbuji *et al*., 2011; Ezegwui *et al*., 2009; Sagay *et al*., 2006; Sadoh & Sadoh, 2009; Titilope *et al*., 2011; Adekanle *et al*., 2015; Ujah, Ezechi & Ohihoin, 2015) reported the prevalence of nondisclosure and reasons for nondisclosure and some (Amoran, 2012; Olagbuji *et al*., 2011; Sagay *et al*, 2006; Sadoh & Sadoh, 2009; Titilope *et al*., 2011) reported factors associated with non-disclosure. Of all the included studies, four studies Dankoli *et al*., 2014; Okareh *et al*., 2013; Adebayo *et al*., 2014; Ogoina *et al*., 2015) did not give a report on non-disclosure participants. The highest nondisclosure rate reported is 60.5% and the lowest rate is 3.3%. The detailed information of non-disclosure is presented in Appendix 9.

The fear of the unknown is common among PLWHA. For instance, the majority of the studies reported that the fear of negative reactions of the recipient influences non-disclosure of status among PLWHA. Six studies (Amoran, 2012; Olagbuji *et al*., 2011; Sagay *et al*., 2006; Sadoh & Sadoh, 2009; Titilope *et al*., 2011; Adebiyi & Ajuwon, 2015) found that fear of what to expect limits disclosure. These include fear of divorce, stigmatisation/discrimination, rejection, abandonment or loss of a relationship, physical abuse, the accusation of infidelity, social exclusion, loss of economic support, the death of a partner and lack of trust.

A study (Ezegwui *et al*., 2009) found that non-disclosure is significantly associated with nulliparous (married women having no children) given p=0.02. Also, unmarried participants were found to be significantly associated with non-disclosure at p=0.02, which is similar to another study (Sadoh & Sadoh, 2009) that reported single mothers were less likely to disclose their status. Risky sexual behaviour, limited access to social services and counselling were associated with non-disclosure (Titilope *et al*., 2011). Participants that had not negotiated safer sex with their sexual partners were less likely to disclose their status; this was common among multi-sexual partners (Titilope *et al*., 2011; Ujah, Ezechi & Ohihoin, 2015).

4.1.8 Quality Appraisal

Appendix 12 gives detailed information on the quality appraisal of the included studies. Sampling in terms of setting and participants was mostly purposive. All fourteen studies clearly described the eligibility criteria for the participants and recruitment strategies. Three studies (Olagbuji *et al*., 2011; Dankoli *et al*., 2014; Adebayo *et al*., 2014) used a statistical power calculation for their sample size.

Of the studies that tested the reliability of the collecting tool (questionnaire), the majority adopted test-retest reliability (Amoran, 2012; Sagay *et al*., 2006; Okareh *et al*., 2013; Adebayo *et al*., 2014; Adekanle *et al*., 2015; Adebiyi & Ajuwon, 2015; Ogoina *et al*., 2015). Six studies carried out a sufficiently rigorous statistical analysis (Amoran, 2012; Salami *et al*., 2011; Olagbuji *et al*., 2011; Sadoh & Sadoh, 2009; Dankoli *et al*., 2014; Adebayo *et al*., 2014; Ogoina *et al*., 2015; Adekanle *et al.,* 2015) while the other six studies (Ezegwui *et. al*., 2009; Sagay *et al*., 2006; Okareh *et al*., 2013; Titilope *et al*., 2011; Ujah, Ezechi & Ohihoin, 2015; Adebiyi & Ajuwon, 2015) provided only frequency tables, graphs, and charts. However, all studies gave sufficient descriptions of the results and the conclusions drawn. Seven studies provided information on the full ethical procedures (Amoran, 2012; Salami *et al.,* 2011; Olagbuji *et al*., 2011; Dankoli *et al*., 2014; Okareh *et al*., 2013; Adebayo *et al*., 2014; Titilope *et al*., 2011; Ogoina *et al*., 2015; Adekanle *et al*., 2015; Ujah, Ezechi & Ohihoin, 2015), three studies (Ezegwui *et al*., 2009; Sagay *et al*., 2006; Sadoh & Sadoh, 2009) only reported seeking (verbal) consent from the participants and a study did not report any information about ethical consideration used in carrying out the research.

Two studies (Dankoli *et al*., 2014; Adebayo *et al*., 2014) had a markedly more rigorous methodology than the rest of the studies. The study design, the sampling strategy, the sampling size, the eligibility criteria, ethical procedures, and the findings were clearly explained, and clear information was given in the two studies.

4.1.9 Summary

The systematic review findings show that a few people kept their positive status completely secret. Various analyses of disclosure showed that choice for disclosure is often made depending on many reasons, such as the trust of the recipient and the timing of the disclosure. Furthermore, the expectation of support is a crucial factor in making a decision to disclose a positive HIV status. People's decision to disclose their status might be dependent on the stigmatisation against people with HIV worldwide and in Nigeria in particular. Whether the non-disclosure has an impact on the incidence of HIV transmission remains to be explored. Fear of disclosure and fear of being stigmatised may result in limited available resources and social support.

Employment is usually the main means of obtaining adequate economic resources for material well-being and full participation in society (Burton, 2010). This is often crucial to an individual's identity and social status. Those who are sick or have some form of illness are also generally better off in terms of health if they can be accommodated in some form of paid work (Burton, 2010). Hence, the number of people living with HIV/AIDS and still gainfully employed has continued to increase due to medical advances in HIV treatment and its management. However, the perception of disclosure in the workplace among employed PLWHA is worthy of research as the decision to return to work after diagnosis is increasing among PLWHA.

The next phase presents the findings of the qualitative study.

Phase Two: Qualitative findings

4.2 Introduction

The systematic review was conducted to understand HIV disclosure among people living with HIV/AIDS in Nigeria and providing the justification for conducting the qualitative phase of the study. The findings from the SR showed the type of disclosure mostly reported among people living with HIV/AIDS in Nigeria was to close relations, especially to sexual partners. However, it illustrated that information on disclosure in the workplace is less reported. Although the SR included only quantitative studies and identified two studies (Salami *et al.*, 2011; Dankoli *et al*., 2014) where very few participants disclosed their status to their work colleagues and employers, there is limited research focusing on workplace disclosure in Nigeria and adopting a qualitative approach. Hence, a qualitative methodology was used to explore the perception of people living with HIV/AIDS on HIV disclosure in the workplace, the psychosocial impact and the practical implications of disclosure.

This phase describes the findings of HIV disclosure among PLWHA in the workplace using face-to-face semi-structured interviews as a means of data collection. The qualitative part of this research explores the sense each participant makes of their self-reflection and the social world while the researcher simultaneously plays a key role in the interpretation of data and development of a coherent research theme (Brocki & Wearden, 2006). This phase presents the main qualitative findings from the semi-structured interviews which were held with patients accessing HIV treatment in a Nigerian hospital.

4.2.1 Demographic information

A total of twenty interviews were conducted. All participants were recruited from the same hospital and were similar in terms of their HIV positive status. The participants were still undergoing HIV treatment and were employed at the time of the interview. Participants were asked to report their highest educational qualification and they range from no formal level of education to postgraduate degree. Table 6 summarises the demographic information.

Table 6: Demographic information of the participants

	Category	Male = 7 (35%)	Female=13 (65%)	No of participants
1.	Age: 18-24 25-44 45-60	 0 2 5	 1 11 1	 1 13 6
2.	Education No level of education O-level GCSE or equivalent Diploma or equivalent. Degree level Postgraduate.	 1 1 2 1 2	 3 3 3 4 0	 4 4 5 5 2
3.	Partnership status Single Married Separated Widow/widower	 0 6 0 1	 2 10 1 0	 2 16 1 1
5.	Year of diagnosis 6 month- 1 year >1-3 years >3-5 years >5-10 years >10 years	 2 2 0 3 1	 1 2 1 5 3	 3 4 1 8 4

The age range of participants was between 21 to 56-year-old. All participants live in Ogbomosho, Oyo state (the town where the hospital is located) (n=19), with the exception of one woman who is from Benue State but works in Oyo town, 31.6 miles from Ogbomoso. Most of the participants described their religion as Christianity, except two participants who described themselves as Muslims. See section 3.2.5 for more details on the selected hospital.

As is mentioned in the methodology chapter (Chapter 6), all interviews were transcribed and analysed using the thematic analysis approach. This involved a detailed immersing of one's self in the data, developing code and generating themes on the perception of an employed person living with HIV, and interpretation of the findings within the context of other research and policy and practice considerations (Silverman, 2012). The extracts from these narratives are presented in the form of themes which were aimed at answering the study's objective. See Appendix 3 & 2(c) for a sample of the transcript showing how the themes were developed. The following are the key themes which emerged from the findings and will be presented in the following section:

1. (a) Making inferences of others' perceptions of HIV

   (b) Making inferences of expectation of others' reactions

2. Going back and forth in making a decision to disclose

3. When it's 'out' you can't take it back

4. Running out of excuses

5. Perceived closeness as a determinant to disclose

6. (a) Visibility of symptoms as a determinant to disclose

(b) Overall health status as a determinant to disclose

7. Disclosure based on associations
8. Meeting workplace regulations and policy
9. Workplace gossip as a determinant to disclose
10. Disadvantageous career prospect as a determinant to disclose

4.2.2 Main findings

The data from the semi-structured interviews generated a wide range of issues for discussion. Details of the process and procedures of data analysis are found in 3.2.7 Data analysis. The following are the main themes that emerged from the interviews conducted among employed people living with HIV/AIDS.

Making inferences about others' perceptions of HIV

Before participants disclose, they have certain perceptions of HIV/AIDS. In most cases, participants reported others having a perception about HIV transmission and how their perception may translate into a decision to disclose or not in the workplace. Participants reported that work colleagues think that HIV kills and as a result, they prefer not to associate with an infected person. With this in their mind, many participants thought that HIV is a difficult issue to talk about in the workplace as illustrated by one of the participants below:

> *'…[Sighed] When I sit together with people and they are talking about the issue saying 'this thing [HIV] kills that person, even I can't eat together with such people', I don't talk [disclose] about it and it's because I haven't told [disclosed] anyone so they don't know my condition' (Female, 32, P12).*

Another participant reported that others believed HIV is a punishment from God for sinners who prostitute but not all that are infected are involved in prostitution, highlighting that innocent children were also infected. Participants, however, agreed that HIV is as a result of sin. That

is why society finds it difficult to accept infected individuals. With others' perception of HIV, disclosure cannot be made in such an environment such as in the workplace. A female participant felt disappointed as she stated:

> *'Um…Some people also think sinners are the ones affected with HIV and you are a prostitute if you have it, …we know it is sin that caused it. It may be different diseases that God is using to punish the earth because of the end time but people think if you are positive, you are a sinner. People that are ignorant don't understand more about it. And not everyone that has it, lived a reckless life' (Female, 44, P07).*

Participants also stated that they cannot disclose their status as people [*colleagues*] lack the understanding of HIV transmission and hence, they tend to dissociate themselves from an infected person, thinking if they sit together with them, they can be infected. Hence, participants highlighted that colleagues who have the 'knowledge' can be disclosed to, while others that lack knowledge of HIV transmission held a certain misconception of HIV transmission as illustrated by a female participant:

> *'It is because people lack knowledge and they take it in another way [they had some misconception]. Some think mere sitting together, you can be infected. People think if you sit together in the same vehicle… sometimes ago, if you stand up from this seat, some people can't sit there; it's because there is a lack of understanding of HIV transmission' (Female, 55, P01).*

Another female participant reported:

> *'You know some don't have the understanding of this thing and some believe if you sit with someone having HIV, you will be*

infected through eating or sitting closely. So, the moment you tell colleagues, they will run away from you.' (Female, 25, P15)

Similarly, a participant reported that the reason why disclosure is difficult to be made in the workplace is that colleagues do not want to identify themselves with an infected person. This makes it difficult to disclose in the workplace. A female participant stated:

'[In a worrying facial expression] it's not easy, this sickness is rampant and not everyone that wants to identify himself with this sickness. It's when you tell somebody, as in, they will select you one side, running away from you as if something is going to... is contagious definitely and you know in a working sector like this, everyone wants to protect his/her own individual' (Female, 35, P05).

Another participant who has lived with HIV for more than 10 years also highlighted that an advancement in HIV treatment has given people living with HIV the privilege to give birth and breastfeed their babies without babies being infected. Hence, she believed that there is hope for more advancement in this area which will eradicate the perception people have about infected individuals who disclosed their HIV positive status.

'Before when you have HIV, you cannot use the spoon he uses, you cannot bath with …, you cannot stay with the person, and before, they cannot give birth normally, they will… they will keep them in a separate Erh.., but now [sighed with relief], they put to bed, they breastfeed their baby, before they don't breastfeed their baby, but now they breastfeed, bring the baby to the clinic, they check you and the baby, when the baby starts to bring out teeth, they stop breastfeeding the baby. And I say there is hope for us' (Female, 35, P05).

Regardless of the perceptions, others have towards PLWHA that prevent them from disclosing their status in their workplace, some participants perceived that disclosure could enhance one's physical and emotional well-being if made to a trusted person. It was identified that sharing one's feelings with a colleague who could keep it secret could contribute to a healthy life free of depression as described below:

> *'Um…When you detect you are positive, share your feelings with someone that you know he/she can keep mouth… so if you share your feelings, you will not be thinking, you will be looking healthy, but if you sit down …So I used to tell people [PLWHA] that it is good for you to tell one person' (Female, 32, P06).*

The reactions of disclosure on others living with HIV/AIDS may have an influence on the perception of an infected individual with a similar condition and his/her willingness to disclose in the workplace. The reactions of others may be beneficial or damaging. For example, the damaging reactions may include losing one's job, domestic abuse and rejection of others as these reactions have an influence on the decision not to disclose in the workplace. A participant reported how the experience of her friend influenced her decision not to disclose her HIV positive status, she angrily said.

> *'Some people say they will make fun of him/her [an infected person]. There was someone, before, she was selling fried yam and Akara and bread… so they had a quarrel and the man sent her away and used her HIV positive status against her. Immediately, every neighbourhood knows and because of that shame, she left the area to another place. Hence, I can't disclose my status at work' (Female, 44, P07)*

As participants make inferences about other's perception of HIV, they also make inferences about their expectation of other's reaction if a disclosure is made. The perception a participant

had has a great influence on their decision to disclose to such a person, group or organisation, or not to disclose.

Making inferences of expectation of others' reactions

Participants' perception of the potential reaction of others can contribute to the decision to disclose or not in the workplace. Participants consider what they think the reaction of others is going to be and hence, base their judgment of the disclosure on it. Some expectation of others' reaction can be perceived stigma, hatred, embarrassment, trust and support. Some participants reported that people who cannot keep a secret, who have a questionable character or lack the knowledge of HIV should not be disclosed to as this could destroy their reputation in the workplace.

> *'When you noticed someone cannot keep his mouth shut, or if the person' mouth is loose, you can't tell him/her. Then, if you look at the character of the person, if the person is knowledgeable, you can tell the person and not just someone that will talk about you, or destroy your reputation, or look at you somehow' (Female, 42, P03).*

> *'What is holding me back [from disclosing my status] is that I am afraid, so he [employer] would not be telling other people and people that don't know about me or my condition, and they would say, 'so, this is the type of person she is. That's why I haven't narrated everything to him [employer]' (Female, 42, P03).*

Participants also perceived that their association with their work colleagues may be affected and this would prevent them from relating with them as they used to do. It was also a concern that the information about their health status would be known to other colleagues and that would prevent them from associating with them.

'People will ignore you when you tell them, and the information will spread. If I tell you, if you see my friend that we are eating together from the same plate, you may not say it directly but saying 'why are you eating with this person' or even if I give the person from what I was eating and the person later knows about my HIV status, I will be isolated (Male, 49, P14).

Participant-related disclosure in the workplace is like advertising oneself on the radio because work colleagues are different in the way they handle things, and hence may relate their HIV condition to others who are not supposed to know. It is believed that personal information such as revealing one's HIV status is difficult to be kept confidential in the workplace as described.

'… [Nodded] You know people are different. If you tell some, everyone in this town will know and it is even better if you decide to go on radio and advertise yourself. The person will tell everybody that this person is having this and that, and this is what is affecting her. So, you can't just tell someone [at the workplace]' (Female, 42, P03).

A participant explained that disclosure can be made when a person has the assurance of who that person is, and he/she is able to keep a secret. However, using that assurance to make a decision to disclose is not enough as colleagues may still show a form of reaction which is damaging towards an infected person such as encouraging people to avoid an infected person.

'Yes, there are benefits even if you want to tell the person, check the life of the person and know his faith and if the person can keep secret, someone can tell the person. But some people, when you tell them they may react somehow and tell everyone

that' you see that person, don't move closer because he/she's got AIDS' (Female, 44, P07).

The participant angrily stated that HIV is not something to be identified with as it could lead to dissociating with such person by colleagues. This dissociation may lead to frustration, hatred, and embarrassment in the workplace.

'The reason is that it [HIV] is not a good thing that people know about someone, that's it and colleagues will be running away from you. I don't like to [disclose], that's it. So, I don't get frustrated by that… people will hate us and spread the information' (Female, 35, P11).

'I didn't tell them because if they know, they will be running away me us, so I didn't tell anyone… I have some people we talk, chat and do things together but they may run away from me saying I have this and that' (Male, 52, P16).

'It's when you tell somebody, as in, they will ignore, running away …I told you nobody knows anything about my condition, and nobody knows. I am alone with it…that is the best way of staying away from embarrassment' (Female, 35, P05).

Participants reported that it was not an easy thing to disclose at the workplace as colleagues who care and love them may stop doing so as a result of knowing about their status. Participants hence believed that it was not an easy decision to make as there is no benefit of disclosure in the workplace as illustrated by a male participant below:

'There is no benefit [of disclosure]. The reason is that colleagues that love you before will stop loving you and they will know what is in the body of that person they are living with' (Male, 56, P18).

The majority of the participants reported stigma as one of the major reasons why disclosure cannot be made in the workplace. The stigma may result in discrimination and maybe even death. For instance, a participant gave an account of what happened when HIV emerged, as families stigmatised the infected person and abandoned the person in a place far away from the rest of their families, hence the work environment may not be a good option to disclose one's status expect when an individual has an assurance of a person they can confide in, and will eventually care for them as shown in a participant's statement below

> '*The reason why I or other people don't disclose in the workplace is that when you disclose, they would start stigmatising you. Before, when people were told this is what happened to this person [an infected person] you brought to the clinic, they would start stigmatising the person. They'll lock the person up in a room, take the person to a faraway village, the person will be there till his/her death. If you have seen a colleague you can confide in, that's better. If you tell the person there is no problem because you will be able to share personal information with each other' (Male, 48, P10).*

A similar perception was reported by a participant who mentioned that disclosure could lead to abandonment as this is what many people want to prevent. Hence, the only way to prevent this is to keep the secret of their HIV positive status from their work colleagues.

> *'If I tell them, they would abandon us so that what we want to prevent may eventually happen to us, so we need to keep the secret' (Male, 43, P20).*

Some participants have the perception that when you do not disclose your HIV positive status, you are free to associate with colleagues. If, however, this is known, individuals will lose the

privilege as people will make such individual feel, as described below, ‘somehow’ or ‘one kind’ as a result of their offensive remarks.

> ‘*You see when colleagues don’t know you have it [HIV], it gives you the privilege to be anywhere you want to be but if you have it, apart from the fact that they will make you feel somehow or won’t allow your body to touch theirs, the person won’t want to go because as the person is coming afar off, they would say the man coming has this’ (Male, 49, P14).*

> *‘Yes, you know, people will be looking at you one kind, you understand. Now, we are all together and doing everything together but immediately they know, they would start saying, don’t move closer to her, she is infected with HIV’ (Female, 44, P07).*

The participant reported that disclosure of status could lead to others making ‘fun’ of an infected individual and may eventually result in loss of employment. The participant highlighted that it is easier for someone who is infected to identify another infected patient through their eyeball. If people that are not infected are able to recognise this, an infected person could be faced with stigma and loss of employment.

> *‘As I am, if I see someone positive, I know them. If I look at their eyeball, I already know what is happening to them. And if someone knows like that, they started molesting the person and making fun of the person, they may sack the person. Some people say they will make fun of him/her’ (Female, 44, P07).*

Some participants also highlighted how their perceived stigma might result in depression, loneliness, sadness, and death. They believed if their relationship with their colleagues changed as a result of the disclosure, they may be depressed and lonely and it may eventually lead to death.

> *'It will make me depressed and may quicken my death. They [colleagues] will run away and that will make someone think too much and if you are lonely or alone every day, the person will die soon. I will be very sad. That's the reason why I didn't tell anyone' (Male, 52, P16).*

A participant mentioned that disclosing to friends in the workplace can be dangerous as there is no true friend. It was further reported that a friend in the workplace can betray one whenever there is any disagreement. It is also possible to have a disagreement with someone in the workplace. However, one's secret may not be safe again when there is such disagreement and the secret is let out. Hence, keeping one's secret should be maintained when dealing with colleagues, but friendship can still remain.

> *'I have a friend [in the workplace]. [But] there is no [intimate] friend except colleagues that we work together only. If someone says we are friends like a brother, it's a lie; it's a lie. No matter your level of friendship; there will be a fight, even, tongue and mouth fight'. No matter how you know how to do it. You fight with your mother, how much more someone born from another home, and you meet, there will be a day you will disagree and the secret you keep with the person will be an instrument of the fight to use for you. That's why I said it's better to keep the secret and continue your friendship' (Female, 28, P08).*

Participant also highlighted that since people understand things differently, it can be dangerous to disclose one's HIV status in the workplace. Hence, some participants reported that disclosure does not have a benefit and will not happen in their workplace. It was also mentioned that since everyone has their personal problems but decided to keep their secret, an individual must decide to keep such secret of their HIV positive status.

> *'Huhumm… I don't think that day will come [to disclose at workplace] because we are all human and we can't trust someone that the person can't betray us. Huhumm… I don't think so because we understand this thing differently and we that are affected understand it but people that don't have it may not understand it… I don't think there is any benefit [of disclosure] because everyone has its own problem but kept it as a secret, so I don't think that there is any advantage there except if they will reveal someone's secret' (Female, 25, P15).*

Although the majority of the participants reported a 'negative' perception of disclosure of HIV-positive status, few participants reported that disclosure can be of help to access necessary care when the need arises. A participant described that disclosure could provide an opportunity to access medical assistance from the workplace clinic and necessary prescriptions can be prescribed in future in case of a need to access the health services.

> '*You see, what actually happened is, the doctors in our (workplace health centre) medical centre, I can't keep my status from them because they may help me with identifying and recommending drugs that are good for me. If I keep my status from them, they may prescribe a drug that may have a side effect to my health' (Male, 48, P10).*

Going back and forth in making a decision to disclose

The findings show that many participants are more likely to hesitate to disclose their HIV status at their place of work. They think about whether they need to or if they do not need to make such a decision and this may bring about a ping-pong effect in decision making. This theme shows the confusion in ping-ponging back-and-forth between the options of either to disclose or not and makes an affected individual think which decision is better, and which one feels right. A participant described her experience with her boss where she felt her boss needed to know about her HIV status due to her past relationship with her boss but was still thinking if this is the right decision to be made or not, as explained below:

> *'…when it got to a stage, I had to tell my boss that I am receiving treatment in Ibadan due to my health and that is the only thing I told him and he used to give me chance [time off work] … I have been thinking that I need to tell him … I said I will, but I have not yet, I am still giving it a thought, however, he used to give me a time when I needed it… but I am not sure the kind of person he is' (Female, 42, P03).*

The participant also narrated her experience of thinking if a decision to disclose was worth it knowing that she might experience disappointment at any time. Also, colleagues' relationship with an infected person may contribute to the decision to disclose their HIV positive status in the workplace or not. Meanwhile, understanding this is not enough to make a decision to disclose in the workplace. This brings about ping-ponging back-and-forth between the two options of whether to disclose in the workplace or not, as described below:

> *'The way we behave to ourselves assures us who they can trust. It is only God we can trust, however, there are some ways some people behave that we may conclude that I trust this person and I am sure he/she can't do this, and it would have been a long relationship. If that trust will remain, fine and if not, there is*

nothing we can do because a human being will always behave like a human being. It may even be that very close person to us can be [sighed], The heart of people can't be seen. If you trust the person and the person disappointed me, it's up to him/her' (Female, 42, P04).

Another participant found it difficult to make a decision to disclose considering her locality and her closeness to others. It was reported that closeness to colleagues can influence a decision to disclose, or not, in the workplace. The type of society one finds him/herself in may stand as a barrier to making such a decision in the workplace. The workplace then seems to be an environment where participants feel less closeness with others.

'I feel that one day, I will tell somebody. It depends on how close I am with the person, how I understand the person. It depends… I will say it one day but before then, one has to be very, very careful, in a local place like this, you can't say it like that' (Female, 35, P05).

The participant could not also make a decision about whether it is the right thing to disclose to her boss or not. She felt that a decision to disclose was as a result of her boss' support in terms of granting her permission to go for an appointment, and some other time he refused to grant such a request, and hence, she was thinking of making a disclosure of her positive status that could help her. However, this decision had not been made yet as described:

'It [HIV] is not a good thing that colleagues know about someone's status …But I have thought about it [disclosure], and this is towards my boss. So that anytime I request for an opportunity to go for my appointment, he will give me. Sometimes, he will refuse, he will shout at me. So, it always comes to my mind that I will tell him' (Female, 35, P11).

A male participant also highlighted the need to disclose to a senior colleague who he claims he had a close relationship with. However, this closeness was not enough to make a decision to disclose his HIV-positive status. This colleague is said not to be his close relative which then put the participant in a situation of deciding whether it is the right decision to make with such a person.

> '*You see, there is one senior colleague that we work together. He is very close to me, he has been transferred, he is now a principal and we are friends. The time I was sick…my mind wanted to tell him [about my HIV status] but I thought of it that he is not my close relative, so I said I don't need to do. I didn't tell him' (Male, 49, P14).*

The majority of the study participants struggle with making a decision to disclose their positive status in their workplace and, as a result, they kept their HIV status secret because they perceived it cannot be controlled by making excuses about their circumstances, and making a judgment of how they can conceal their status by recognising the visibility of their symptoms and their overall health status. These themes will be discussed as a way of limiting the possibilities of disclosure of status in a working environment.

When it's 'out', you can't take it back

Participants reported that their decision to disclose their status in the workplace resulted in other colleagues' awareness of their status. They believed that once the information is out there, it is difficult to control the trail and it is never a secret again. Some participants did not expect this would happen to them because they believed that their recipient had an understanding of HIV, but eventually disclosed their status without their consent as described by a female participant;

> *'You know such spreads easily and if someone should hear it… if it's a secret, it's better not to tell anybody. If something is a*

secret and you talk about it, the person will tell another person, and it continues that way, so that was what caused it…those things made me cry' (Female, 27, P13).

Another participant reported that his information became the talk of the 'whole world' as his colleague informed others, which was not what he was expecting. He was concerned about such information getting out that cannot be taken back as many people know through this means.

'My friend who tested me is a medical doctor; I am a nurse by profession, I am a trained nurse so I managed a hospital in the North. I didn't envisage such a thing would happen. He begins to tell some of our church members my status. It becomes the talk of the whole hospital, saying 'have you heard …he has got infected'. This information went out of hand and I can't control it' (Male, 40, P19).

As people living with HIV/AIDS go back and forth in making a decision, they are also concerned when the information is out, as they cannot take it back. Hence, within this time of an internal ping-ponging back-and-forth between the options of either to disclose or not, they start to present excuses in their workplace to gain some support needed to manage their condition.

Running out of excuses

Participants reported that disclosure of their status could be quicker when they start running out of excuses for why they are absent or inconsistent at work or having the low morale to perform efficiently at work. They reported making excuses a difficult one as work colleagues get suspicious of their situation if they found that their excuses did not sound genuine. This consequently left them in a situation where they needed to consider disclosure of their HIV-positive status. Meanwhile, some participants were able to continuously generate excuses for

their absence in the workplace as this would also be reported under this theme. The majority of this study's participants use the word 'check-up' to report the reason for their hospital visit as it is expected that an adult gets checked regularly, and hence participants do not have to give reasons for what that 'check-up' actually means.

A participant reported on the need to present an excuse that will not be difficult to defend or will not be suspicious. Hence, the participant is of the opinion that making excuses of going to visit someone in the hospital consistently could be suspicious and could generate concerns among colleagues of the real need for constant hospital visits. However, telling other colleagues he wants to go to the town centre does not sound suspicious as many things can be done while going to the town centre as described by the male participant who had lived with HIV for two years at the time of the interview;

> *'I may say I want to go to town and you know it will be difficult to say…if I tell them [colleagues] that I want to go to the hospital, they understand I may want to visit someone but between the space of 2 months...I must explain that' (Male, 49, P14).*

Similarly, a participant also gets away with providing excuses to justify their reasons to be absent from work. When such excuses are justified and acceptable to their work colleagues or their employers, they continue to make their status a secret. There were excuses that generate empathy from the participants' employer according to this study. These include issues with families, especially their children as shown in the quotation below:

> *'Most time, I do lie because I don't want them to know. I lied by saying I want to pick my child from school, or I say I am going somewhere with my husband and my boss is very nice; he will give me a chance' (Female, 25, P15)*

A participant highlighted the need to give different reasons at different times for being absent from work. Different reasons such as a need to go for a check-up, and at another time the

need to attend to personal commitments. It was believed that generating acceptable excuses could mean a person can continue to keep his/her HIV positive status secret.

> *'Sometimes, I say I am going for a check-up, could you please give me chance? Another time, I can say, my boss, I won't come tomorrow, I have somewhere to go' (Female, 32, P12).*

It was highlighted by some participants that an employer's understanding of their previous illness could make it less difficult to get permission from their employer about going for a 'check-up', although, saying this consistently may generate questions of when the hospital visits would stop. A participant reported how this was handled as she said her regular check-up is also needed by everyone even if you do not have any illness. It was reported that regular check-ups gave an update of one's health status to avoid unexpected illnesses as described by a female participant who had lived with HIV for more than 7 years at the time of the interview;

> *'My boss didn't know but he knows I was sick sometimes ago, so I told him they said I am now their patient and that every month, I must come for a check-up, so whenever I want to request for permission, I always say I am going for a check-up. They sometimes ago said, Ha, why is it that all the time you go, hasn't it stopped; its more than three years? I said even you; you need a regular check-up, so you just don't collapse suddenly. For me, going to the hospital regularly for a check-up and for you that have nothing presently wrong with, all need a check-up at least six months. So, when I told them that, they stopped saying things about the matter' (Female, 28, P08).*

Another participant reported a similar situation where she needed to inform her boss about her serious condition which warrants regular checks, and her boss had always been supportive.

> *'I inform my boss here in Xx that we work together that tomorrow is my check-up and they would say, no problem…I didn't say this was exactly what happened to me. I just told them that I was sick, and it was very seriously' (Female, 35, P17).*

The type of work and work duties determine how easy an individual can take permission at work to go for an appointment. A participant reported that her work duties did not permit her to be absent from work at any time as this made it difficult for her to take time off work. It was highlighted that she needed to attend 'bleeding' (checking one's CD4 count) by herself, but she struggled to tell her boss she wanted to go for her check-up. Although she was worried that saying this every time would cause suspicion, this influenced her to consider disclosure of her status to her boss

> *'You see my type of work…, I have to leave the job [take permission] no one can do bleeding for me unless I get there myself. And also it is very difficult for me to leave that time in my type of work, I still need to go to my boss and explain this and that,but when it is every time[taking permission], you see' (Female, 42, P03).*

Some participants were able to prevent giving excuses by not going to hospital appointments monthly as expected as they had built a relationship with hospital staff to collect their medications for them. This prevents taking permission monthly for a hospital appointment which may bring about suspicion. It was reported that hospital staff could make it easier for some patients to pick their medication without it affecting their work or putting them in a difficult situation of disclosing their status as a result of their frequent absence. Hence, medication

pick-up could be arranged with some of the staff for some patients to pick up their medication at their convenience. A participant reported that one of the staffs assisted her in picking up her medication except during the time of 'bleeding' where she needed to be there herself. A bleeding period is reported as a period where doctors accessed the viral load of an infected patient to understand the CD4 count. This reduces getting worried about finding excuses for not being at work.

> *'Staff A assists me to pick my drugs from Ibadan but whenever we want to have bleeding, I will go during the 'bleeding period' and do 'bleeding' myself, as long as I don't have any problem or anything that is serious that could take me there [to the hospital] to complain' (Female, 44, P07).*

Another participant reported that going for an appointment did not disturb her job at all as she could request one of their staff to get her medication for her and without having to provide excuses for attending a hospital appointment. This could be picked up after working hours where there would not be many patients around and staff would be less busy, as reported by a participant who had lived with HIV for more than 9 years.

> *'It doesn't disturb my job at all. When I am at work, maybe on a morning shift, when I get to work in the morning, I will tell one of their staff to get my card and I will go for vital science and things like that. And in the evening, when I noticed they are no busier with other people coming from outside, I will go to the clinic and pick my drugs. No problem' (Female, 42, P04).*

However, some participants reported that they had not experienced being in a situation where they would have to explain the reasons for their regular hospital visit. A participant who had lived with HIV for 6 years said he informed his general manager about going for his appointment as the day got closer and he did not have any difficulty trying to convince his

boss of the need to be absent from work, nor finding excuses to present to his colleagues of the reason for his absence. Another female participant who had lived with HIV for 10 years also supported this view that her boss never asked her what sort of appointment she was going for as she informed her in advance of her appointment date of the need to be absent from work and it would be granted, as described below:

> '*Whenever the appointment date is close, I will tell him…., like yesterday, I will say that I am going for a check-up. No one has ever attacked me on this. When it's close to the date, because I am the manager for my department, and when I inform my GM (General manager) that I am going, nothing will happen' (Male, 56, P18).*

> *'When I feel weak, I would just take permission, I will tell my boss at work and she would tell me to go and rest and if I go to Ibadan, and because I didn't disclose to them what is wrong with me, I will just tell them, I want to get [for my check-up] .. So, I will just tell her, 'Mummy [Boss], tomorrow or next, on Wednesday, I will go to Ibadan, and on Tuesday, she would say, you can go, no problem…She doesn't bother me; she won't ask me what I'm going there for' (Female, 44, P07).*

A similar situation was reported by a participant who said because of his work performance, he could request to go for a check-up monthly without anyone asking him what sort of check-up he was going for. It was found that satisfactory work performance could give an individual the opportunity to take time off work without giving reasons or without any colleague asking what the request was meant for. This was described by a participant who had been diagnosed for 10 years;

> *'I collect my medication once a month and when it's time to go, I inform my colleague in the office that I am going for a check-up;*

they will not know what check-up I am going for, but I know within me what kind of check-up I go for. If I say I am going for a check-up, no one can say anything because I don't play with my job and [I work] with all seriousness. Like this morning, the work I have done is enough to take some people a whole week to do' (Male, 48, P10).

In other cases, participants whose work was in a shift or part-time found it easier to go for their check-up without being worried about what to say or what not to say. They found a means where their appointment did not fall within the working hours to prevent finding excuses for being absent from work. This also made it easier to get their permission request granted when there was a need to request for one as described by a male participant;

'[Sighed with relief] …You know my type of work is a shift pattern. I have my [hospital] appointment when I'm off work; I don't have to inform them, so they don't have to know every time. Like now, I'm not at work so they won't know I am here but maybe next month, I may, and I may not be at work so it's not every time. It [my job] is not regular; we are 3 people rotating the shift doing the security work. Even within the security staff, they didn't know [because] I don't take permission every time' (Male, 52, P16).

The participant was of the opinion that requesting a hospital visit consistently or finding excuses for not coming to work may put an individual's job at risk. Hence, he decided to have a discussion with his doctor to give him a convenient time which will not affect his work such as the end of the month appointment when the organisation is off for a break. This prevented him from ever requesting permission to be absent from work.

'I have discussed with my doctor that I preferred the end of the month because of that time, the last Thursday of every month,

we have a break at work and the second day which is Friday, I will come and take my drugs. It has never happened before. Even if you don't have any problem and you start requesting for a time off regularly, they would assume you are not ready to work, so they would just give you a stay off note that you are missing work' (Male, 43, P20).

If an infected person cannot get away with presenting more excuses such as going for a check-up, the person runs out of excuses and a need arises to make a disclosure of his/her status. A participant recalled his experience when the organisation he worked with could not take him seriously anymore whenever he wanted to go for a 'check-up' because his boss would suggest that he could use the weekend to go for a check-up or other days, hence a need to tell his boss of his HIV positive status.

'Yeah, sometimes, because of my office, a lot of things come to my table, sometimes if I tell them I need time for my personal... they don't take it seriously but if it is health related, so sometimes, I have to tell them I need to go for check-up so . and I think there was sometimes I need to call my boss, the head of the organisation and said, look, I am positive, I need to …its, not just any… I have time because she was saying you can go for a check-up at any time now, you can schedule a weekend, you can schedule Friday, so I have to call her and tell her. That's how she knows' (Male, 40, P19).

Daily medication intake, especially in the workplace, puts participants in a situation where they have to give some reasons why they take such medication especially when this is seen by their colleagues regularly. Some participants give excuses that seem acceptable to people,

while some, to avoid this, made their medication intake fall outside their working hours to avoid giving excuses for the medication they were taking.

A female participant highlighted that colleagues get curious when there is daily medication intake in the workplace. This opens up discussion about trying to find out what exactly is going wrong with her health that warrants taking daily medication. In this situation, an individual was put into a situation where she needed to lie to cover up her real situation as described below:

> *'And if you are taking your drug at work, they would ask you what the drug is for, why taking it, what's wrong with you? Then you have to be lying for one thing or the other, at least. It is office work, we take drugs, but they would say 'Ha, do you have a headache, what are you taking drugs for?' It's a normal thing to take drugs, but they want to really know what happens to you' (Female, 35, P05).*

Another participant shared her experience at work where she needed to give various excuses of why she was taking medication every day. It was mentioned that she needed to put her tablet on her office table to give her a reminder not to miss her medication intake. However, this generated curiosity from her colleagues of why she was taking medication daily. She gave excuses such as feeling ill, not feeling comfortable in her stomach, a need for a regular health check or pills for family planning.

> *'Yeah, some people do ask me, I will just say, I am ill, I may say, I am feeling uncomfortable with my stomach, … I sometimes forget to take my medication so when I realised that, I will put it on my table. There was a time a woman approached me and said why do you use drugs every day and I said you know we, ladies, we need to always take care of ourselves, it is compulsory a woman takes care of herself. Another day, I responded to*

someone by saying there are different types of family planning, there is one that you must use drugs every day and not miss it' (Female, 42, P03).

Some other participants gave excuses for taking medications which included taking medication for a less stigmatised condition or lying about a previous illness that was known by their colleagues which required long-term medical treatment. Participants disclosed but did not disclose exactly their condition; they disclosed a less stigmatised condition to earn support from their employer. This is referred to as a *false disclosure* in this study. Participants are able to cover up with other less stigmatised conditions such as diabetes, high blood pressure, malaria, asthma.

Among participants who disclosed less stigmatised conditions, a participant reported that it was easier for her to attend her hospital appointment as her boss granted her permission because of her previous illness of malaria. It was mentioned that she may sometimes feel weak and request to be absent from work, and permission would always be granted without having to disclose her HIV positive status to her boss.

'The woman doesn't bother; she won't ask me what I'm going there for. I will say Mummy [the boss], I want to go to Ibadan for some things …. malaria used to cause that because I regularly have malaria then. So, when I have malaria, I will tell my boss, I may even call via phone that I feel weak and won't be able to make it work. She would pray for me and would tell me to take care of myself. Sometimes, she may visit me in my home' (Female, 44, P07).

Another participant, due to her known asthma, found it easier for her colleagues to give their support as they believed she was still receiving treatment for her previously known asthma. It

was then easier to take her medication at work and go for her hospital appointment without finding excuses for her absence.

> '*You know your kind of pretend and feel normal because you know I have asthma They are now seeing that it's that asthma that I use drugs for but for me, I know it's not asthma' (Female, 35, P05).*

The majority could get away with these excuses since the medication is difficult to recognise especially among people who are not under treatment, are not infected or are not carers of someone having HIV. This makes it easier for people to lie about it, especially participants for whom the time of their medication intake falls within work hours. Participants also said that for anyone to recognise it, he or she must be infected or have someone who is infected.

> *'…because I don't take the container with me but if I see it, I will know it, and if someone should recognise it, that means, he/she has it, we are the same, or has someone who is HIV positive too' (Female, 42, P03).*

Participants highlighted that since the drugs are difficult to recognise and can be mistakenly taken for another common drug such as paracetamol, it is easier to take medication amidst people. It was also noted that to prevent suspicion through the use of medication at work; the medication package should not be taken to work together with the drugs.

> '*I don't bring it out. If I am going somewhere or travelling, I take what I need into a small plastic bag, and no one will know especially septrin, someone would think its paracetamol' (Female, 35, P17).*

Another participant reported a similar experience where the use of a medication package could make people be suspicious of her condition, but if the medication is stored in a different

container, an infected person could take his/her medication at the workplace and in the presence of his/her colleagues freely without fear of disclosing one's status.

> '*You see, HIV drugs, as for me, I will take a small plastic bag for medication and put my medication inside it. It cannot be recognised except someone that knows drugs or about HIV, and if I sit with people, I could bring out my medication and use it; it's because they don't know about it except for someone that can recognise it' (Female, 32, P12).*

The participant also highlighted that even if the name of her medication was mentioned to people who were curious to know her medication, they were not able to understand the condition which the drug is used for, but separating the tablets away from its original container stops people being suspicious of one's condition.

> *'Yes, people do ask, especially people that see it. For me, I keep it very well, and these drugs make a lot of noise in its container. So I take the ones I need for a day or if I want to travel, I do take extra in case my stay there was extended and put it into a plastic bag. However, wherever I stay, people I stay with may sometimes ask what type of drugs I am using and I will mention the name because they don't know about it, the drugs look the same' (Female, 27, P13).*

Some participants believe they do not have to give an explanation of their condition or the medication they take as there are many people using medication for various conditions which could make some people less bothered about what medication other people take. This opinion could be easier to be held due to the length of time an individual has lived with HIV and the coping mechanism to deal with this situation whenever it arrived. A participant who had lived with HIV for more than ten years at the time of this interview explained that because others

also use medication for lots of condition, they do not bother to ask what sort of medication he is using, as described below:

> *'No one can ask me such. This life is simple; no one can ask another what type of drug you are using because now, there are so many conditions and almost everyone has a medication he/she uses in the morning. If you are not on high blood pressure drugs, you will be on another medication for a particular condition. The herbal product they sell everywhere, some people had to use it every day that's why no one cares to know the type of drugs you use. No one can say anything' (Male, 48, P10).*

Another participant who had lived with HIV for more than 12 years also reported that meeting with other people living with HIV in a support group meeting had improved his confidence not to always have to give an explanation of what medication he was using, although he stated that this was an issue at the initial stage of his diagnosis. He also described that many people take medication for one condition or the other which they do not make known to people.

> *'At the initial stage, people keep asking [at work], what is your problem? Why are you taking this drug? There are several instances as at then, well it doesn't take me long because of the support group, and I met people who want to understand then later I discovered that I don't need to give people an explanation. 'Which drugs are you taking?' It's my drug. Which one are you taking? Which one do you want to know? Later I discovered that people hide away their drugs. I later also discovered that it is people who use the drugs that knows the drugs or people who work closely with those people that know the drugs. You cannot just tell everybody, so I bothered less but the support group*

gave me the confidence and also travelling out has given me the opportunities to meet several people' (Male, 40, P19).

However, some participants do not have to fear who is going to ask them what type of medication they use daily as the time of their medication intake falls outside work hours. Some participants reported that to avoid curiosity of their colleagues, they did not take their medication at work, which is twice a day, but it was taken outside working hours. These enable them to avoid making excuses for taking medication for their conditions as described by some participants;

'I have never taken my drugs at work; I use it 6 am and 6 pm. We close work at 2 pm. I use it inside the house, in my sitting room or my bedroom' (Male, 49, P14).

'No, I use it in the morning before leaving for work and take tea, and when I return, I take it in the evening. Whenever I am travelling, it is always with me' (Male, 56, P18)

Participants in this study had highlighted that finding excuses happened when they needed to cover up their reasons for attending regular hospital appointments or when they took their medications at work. Some participants were able to manage this situation by reporting previously known less stigmatised condition such as asthma or malaria, while others mentioned that they were not under any obligation to give an explanation to anyone for their condition as people do have one condition or the other that they are dealing with. However, participants who feel finding excuses may not help them had to disclose based on their previous relationship with their work colleagues or their employer.

Perceived closeness as a determinant to disclose

Participants highlighted that the decision to disclose one's status in the workplace could be based on the closeness they felt with others beforehand. When an individual has established

his/her level of closeness with other people, they can make a decision to disclose their personal information, trusting them that it would be safe with them. A participant reported that he could only disclose to people in the workplace that are close to him as his boss had a close relationship with him when he was diagnosed and his boss seemed to be the only person that could be trusted at that time.

> *'I told my boss because she was the only person I could tell during that period. There are some people you can't tell then if I had told my wife immediately, she will abandon me during that period. If I had told my parent, they would abandon me but while the woman knows, she did not abandon me, because she is the only one that I can trust' (Male, 48, P10).*

However, some participants see their closeness with others as less important when considering who they need to disclose to. While some participants believed they needed to disclose to their families, others believed that their families do not have a say in their decision making. Meanwhile, some participants reported that for as long as they do not disclose to their family members, disclosures to others in the workplace are insignificant as it is termed disclosure to an '*outsider*'. This means disclosure in the workplace is not what they consider.

> *'No, if I cannot tell my mother that born me, I cannot disclose to another outsider' (Female, 35, P11).*

Similarly, another participant described how disclosure to family members differs from disclosure in the workplace. Disclosure needs to be done carefully as it cannot be easier for a person living with HIV/AIDS to trust someone in the workplace than it is with their family members. Hence, closeness to a colleague at work does not guarantee that an infected person should open up about his/her condition as described below:

> *'When you know that this person will not tell another, you may then tell them, but you should not trust other people like that even*

people that are positive, especially if they are not your family members. To me, my family or any close relations are the ones I can tell' (Female, 21, P02).

As disclosure could be based on proximity, for some participants, their decision to disclose their HIV positive status was based on their external look or the visible symptoms they possess.

Visibility of symptoms as a determinant to disclose

Participants highlighted that disclosure is linked with how visibly the condition is revealed to the colleagues, and specifically, in their work environment. Since participants included in this study were employed people living with HIV/AIDS, the visibility of their symptoms influenced how the decision to disclose or not was made. Participants resumed work after recovery and based their decision on their appearance and fitness to work. When there are no visible symptoms of HIV, people do not bother to disclose.

A participant reported that since she has recovered, she has not fallen ill and the symptoms of HIV are not visible to others anymore, hence the reason why disclosure of status may not be necessary for the workplace.

'I don't fall sick and I won't and there are no symptoms showing, so why will I disclose' (Female, 42, P04).

An invisible illness provides more time for a person to evaluate disclosure before it is made. A participant said HIV is not a visible illness that could make a lot of people aware and as long as it does not appear on people's faces, disclosure may not be necessary except if an infected person decided to disclose his/her status, as described below:

'If not that I tell someone myself, as you are asking, no one will know. It doesn't show on faces or in appearance' (Male, 52, P16).

Another participant reported that the way she looks makes people unaware of her HIV positive status, and that makes it unnecessary to disclose her status in the workplace. Having an invisible symptom could reduce the pressure to disclose in a working environment where access to support does not require disclosure.

> *'I have a lot of them (bosses) but they haven't noticed anything due to the way I look' (Female, 42, P03).*

Similarly, participants also highlighted that their decision not to disclose was based on the reason that their appearances do not look bad and the use of their medication as prescribed had maintained their good health. It was also mentioned that since they did not visit the hospital for any opportunistic infection, there was no reason for them to disclose their status in the workplace, as described by some participants below:

> *'No, I can't say it, never…Never, I can't tell anyone, and nobody will know, my appearance isn't bad and since I have been using my drugs, I haven't come to complain of any other thing [problem]' (Female, 35, P17)*

> *'When people see me, they will know that I am healthy and also taking my drugs regularly. No one will notice anything' (Female, 32, P12)*

Some participants mentioned that work colleagues would not believe them if they chose to disclose their HIV positive status because their symptoms were invisible. It becomes clear that a visible physical illness creates a concern and makes work colleagues suspicious, leading to social segregation but invisible symptoms might help in limiting disclosure of HIV positive status.

> *'If I tell them, they won't believe me, …this is because when you look healthier than somebody who [doesn't have HIV] … if you*

look at me, do I look like an HIV positive patient? No,' (Male, 52, P09).

Another participant reported her experience that people could not believe she was positive when the news of her status broke out in her workplace. She said this was because of her outward look when they all said it can never happen to her as described below:

'They were all saying, 'how can that happen?' With the way I look, they said it can never happen. She said they know I have tested and didn't believe that because of the way I look, I can't have such, saying it's not possible' (Female, 27, P13).

However, some participants reported that an absence of visible symptoms gives the confidence to give advice to newly diagnosed HIV persons who believed an HIV infection means an end to one's life. In this situation, participants that had lived with HIV positive status for 10 years or more had more confidence to counsel newly diagnosed people about their condition. They also found it easier to use themselves as an example of how to live with HIV and being able to leave a productive life.

'I will encourage the person and say look at me, can you believe I have it, many of them don't believe me' (Female, 42, P03)

Similarly, a participant reported that it could be difficult for people to know her status until she disclosed her HIV positive status. Her invisible symptoms coupled with her recovery have given her the confidence to use her condition to counsel others who were infected. This counselling aimed to give them hope of survival, as described below:

'It doesn't show in appearance. If many people are in this room until you tell someone you have it. But I will be happy to say this in the future. Because I was saved and recovered and the

opportunity, I have… one should strive not to let another person die' (Female, 25, P15).

Visibility of symptoms is what many participants used to judge their decision either to disclose or not in their workplace. A disclosure of their positive status may not be necessary if there is no physical symptom of HIV, and this made the majority of the participants report that people may not believe them even if they disclose their status due to their invisible symptoms. Overall health status is also found to be more important in a decision to disclose: it not only maintains the fact that people do not disclose due to having invisible symptoms, but they may or may not consider disclosure due to their overall health status. The themes: visibility of symptoms and the overall health status have been developed into an article and submitted for publication. See the abstract in Appendix 14.

Overall health status as a determinant to disclose

The overall health status of participants was also acknowledged as a reason to disclose in the workplace or not. It was reported that the significant changes in their overall well-being and recovery compared to when they were first diagnosed were other reasons why they may or may not consider disclosure of their status. For most people, their overall well-being made it unnecessary to disclose in their workplace. A participant reported that at the initial stage of diagnosis, he was feeling unwell and consequently lost weight but when he recovered, he stopped experiencing such and since he is now okay without any 'problem', there is no need for disclosure.

'During that period that I was sick, about a month or more, I was home then, and the reason why I was home then was that I lost weight that time and when I recovered, that was it and since I have started work. I don't think I had a headache that couldn't allow me to go to work and could warrant telling someone about

my status. I don't have any problem as long as I am taking my drugs' (Male, 48, P10).

The participant gave an account of different opinions people had when he was unwell at the time of diagnosis. This led to colleagues being suspicious of her status. However, due to her recovery, people were confused about her status and they assumed they were wrong in the first place.

'*When I was out of the hospital, people were talking, because I have lost weight. So, people were saying it around, she has contracted HIV, they have used her, you know especially for people like me that is flashy and fashion conscious, so they can say anything like she's got HIV, they have used her and different things. So, when I recovered, they were the ones telling me that they were wrong for saying such at that time but they didn't know and that is because I am taking my drugs regularly …' (Female, 27, P13).*

A similar situation was also mentioned by a participant that their improved overall health status after they had been placed on medication, assisted them to resume work without making disclosure of their status. At the initial stage, people were suspicious of their status but when he recovered, they were unable to believe that he was HIV positive, as described below:

'When I used the drugs, within 2-3 months of using the drugs, I resumed work. People that have said I had HIV/AIDS came to beg me when I recovered and told me what they have said at my back, but I know what is wrong with me anyway … No one knows anything' (Male, 48, P10).

A participant highlighted that when she recovered from her illness at the initial stage of diagnosis, no one asked her at work about her condition because she had recovered from her

illness. Hence, recovery reduced the pressure to disclose her status. It could also make individual decisions not to disclose easier, especially when it is no longer affecting their work performance.

> *'When it started, it was on a Friday, so I rang my boss on Saturday that I won't be coming to work on Monday that I was sick. When I didn't go to school [work] on Monday and Tuesday, so I resumed on Wednesday, so when they noticed how I was feeling, they told me to go back home and return to school when I am perfectly okay so since then that I noticed I have recovered; I didn't feel weak or vomit again, no one asked me anything again (Female, 25, P15).*

The participant also reported that there was no need to tell anyone at work about his condition since he had recovered as disclosure could damage one's personal identity in the workplace if care was not taken, as described below:

> *'When one is okay, you need to be careful of what can spoil one's reputation…but since I know everything is okay, …God has made me recover and I am using my drugs daily' (Male, 56, P18).*

However, a participant reported that her recovery could make her plan a disclosure, especially for people that are newly diagnosed who thought they could not overcome it. It was also highlighted that if an individual has recovered, it should not be a thing of shame to tell the public so that this would help others to get tested or to receive treatment, as described below:

> *'I don't want to hide for people again. People that are newly diagnosed could be reassured because some people feel like poisoning themselves and that is not good. But now, I have overcome it, it's now getting to 5 years and even more. I don't experience any problem again, no sickness and I am okay now,*

even if they say I should go in public, I don't care. Because when they see me that I am okay, it doesn't bother me, there are so many conditions that are worse than this' (Female, 42, P03).

Another participant also reported that when an individual is following treatment instructions and they recovered from their illness, it should not be a 'big deal' in telling colleagues their status. The participant reported that he felt healthier than when he was initially diagnosed and that should give him the confidence to tell people when asked about his status, as described below:

'Actually, if I tell anybody, nobody will believe me. Even as I am talking to you now, if I say I have HIV, you will not believe me because I know the level that I was before I noticed it, I used to feel tired, stress, everything but those things is no more there again. But now that I am placed on healthcare, receiving the treatment regularly, follow the instruction. I mean, I don't think it's a big deal to tell if anybody asks me. What is the big deal! I feel healthier than before when I don't know that I was having this sickness. I look at everybody like this, I could say I'm healthier than people that don't have HIV' (Male, 52, P09)

Although the majority of the study participants highlighted that disclosure may not be necessary if an individual has recovered from his/her illness, a few participants argued that disclosure could be made when a recovery is made to give hope to others with a similar condition that had lost hope. This type of disclosure to newly infected patients will be discussed next as people based their disclosure on association: people with the similar or the same condition.

Disclosure based on associations

Disclosure based on association in this study means disclosure to others who live with HIV or similar conditions. The majority of the participants reported this type of disclosure as a way of giving hope and assurance for someone who is newly diagnosed or someone who is confused about how to live with HIV/AIDS. Some participants also reported, according to their experience, an 'insider' to be someone having similar HIV positive status. It was found that it was easier to disclose to someone having the same HIV-positive condition than someone who is negative or unsure of his/her HIV status. The duty of care can be extended to such person particularly, to give advice on the management of HIV and of its recovery. A participant reported that it was easier to disclose her positive status in the workplace for people with whom they work together and were also infected with HIV. It was also highlighted that more disclosure can be made if there was an opportunity to meet someone who is new and needed to be assured of hope to live with it as described below:

> *'Yes, they know… we work together, we are the same [same HIV status]. I can also disclose if the person is positive, I can tell the person and use myself as an example. I can tell newly diagnosed that he should not think about it, and I would say 'as you see me, I am positive', and that would encourage the person not to lose hope (Female, 21, P02).*

A participant highlighted it was easier to tell people that are newly diagnosed with HIV to encourage them to start treatment and to assure them of the hope to live with it. It was also noted that her length of time of living with this condition had given her confidence because, even if it was necessary to go public and counsel people, she did not care as what was important was to convince others that there are so many conditions worse than HIV. This is described below:

> *'I used to tell people especially, the newly diagnosed patients…I don't want to hide it anymore especially for people that are newly*

diagnosed because some people feel like poisoning themselves and that is not good. But now, I have overcome it, it's now getting to 5 years and even more. I don't experience any problem again, I am okay now, even if they say I should go to the public, I don't care. Because when they see me that I am okay, that doesn't bother me, there are so many conditions worse than this' (Female, 42, P03).

A participant said he had been called upon before to give advice to someone who was newly diagnosed when he was recovering from the symptoms and following his treatment instructions, as described below:

'I tell colleagues. If you ask them… when I was recovering and I was using my drugs and getting well, I did it. I joined a support group, and if I come to the hospital, they will call me and I will talk to the person' (Male, 56, P18).

Some of the participants also said although they had not seen an opportunity to disclose to someone living with HIV in their workplace, if there was a situation whereby a colleague was infected with HIV and needed advice on management, they would be glad to provide help. A participant reported that disclosure can be made when someone is in a 'poor state of health' and needs immediate intervention. Advice could be given to convince the newly diagnosed that they can live with this condition if they go for treatment, as described below

'When I see somebody that is dying from it, I would boldly tell the person. Do you know I have HIV; do I look like someone who has it? But I have it. Please, go to the hospital, do this, do that, you will be fit, you will come back to your feet, you will be okay, everybody will know. When I see somebody and see that he

didn't know, when I see somebody if really he is suffering from this thing too, I will tell the person' (Female, 35, P05).

Another participant reported that if there was an opportunity to meet someone who was diagnosed with HIV and needed advice on treatment, she was happy to use herself as an example to counsel that individual. However, it could be frustrating if the person did not want to receive treatment and later died, as described below:

'If they bring someone and I know that person needs treatment and care… I will use myself as an example I used to tell them (people with similar status) but it used to be painful when you tell some people and at the end, they don't wait to receive treatment again because they will not believe, especially if the person later died, they won't believe you are saying the truth (Female, 55, P01).

A similar situation was also reported that disclosure can only be made to someone who is infected if he/she first disclosed and is ready to go for treatment, but disclosure cannot just happen to anyone unless the person first opens up, as described below:

'If I see someone that has it and the person voiced out that he's got this thing or he was worried, I may advise the person that he shouldn't harm himself or commit suicide and that I am also infected and so many people that are positive are living and are not dead, so the next thing is to get proper care and start getting medication. If you are not alive, there is no hope. So, I can tell someone that has it. If the person is not infected, I don't think I've got that boldness, I may also be ashamed to say that I am HIV positive' (Female, 25, P15).

It was also said that if the symptoms of HIV are seen in someone, the person can be assisted to go to the hospital and if eventually the person is tested positive, then disclosure can be made knowing fully well they both have a similar status as described below:

> *'Without being a doctor, if I see maybe the person is having frequent sickness and could notice the same symptoms I had in that person, I will be the one to bring the person here. So, if they carry-out the test and the person is positive, I will then explain myself that the way it affected you is the way it happened to me too that's why I brought you here, I have it too' (Male, 49, P14).*

Meanwhile, a participant maintained that disclosure of status to colleagues who were newly diagnosed and did not know what to do next was very important for their psychological support. The participant gave an account of his experience of visiting a doctor who had been living with HIV for about 20 years to get advice from that individual. This participant claimed that getting that information made him feel he was not alone and that he had hope to live again, as described below:

> '*One of the good supports shown at that time is to see others who have gone through the situation and have survived. Another person that gave me hugely was a medical doctor who was HIV infected; I had to travel to see that person, the person was like, 'look, that's not the end of life'. In fact, the person is almost like 20 years living with the virus. So those are some of the psychological support; feel belonging, somebody comes around, counselling, giving hope etc' (Male, 40, P19).*

It was also highlighted that disclosure of status does not have to be made when counselling people that are newly diagnosed. Advice can be given to that individual, but personal information can also be protected. Participants provided help by counselling newly infected

people or an individual they assumed had the symptoms of HIV. In this case, participants reported that they did not have to disclose their status but would go ahead and advise them to visit the hospital.

> *'So, I used to advise people to go to the hospital although won't tell them exactly what is happening to me but would tell them how I went there and I knew what was happening to me and how they rendered help' (Female, 35, P17).*

This theme has highlighted participants' view on why people living with HIV feel it is the right thing to disclose to others who are living with HIV. Participants disclosed to others due to their present situation, to assist them to start treatment, to give hope to live a longer life and to make them believe in themselves again. It was also highlighted that this support is very important as it helps people psychologically in the management of their stigmatised condition. Although not all participants have disclosed to someone who is newly diagnosed, the majority mentioned that they were willing to do so, while a few others said they could only disclose when such colleague had been confirmed to be HIV positive. A contradicting view was raised by a participant as it was reported that disclosure of status is not necessary when counselling people as long as advice can be given to a newly diagnosed person on management and treatment. Meanwhile, some participants disclosed because they needed to comply with their workplace regulations and policies: such disclosure may not be negotiable, as detailed in the next section.

Meeting workplace regulations and policy

HIV testing or disclosure is compulsory in some working organisations. Participants reported that they were in the situation where they needed to disclose their HIV status or go for HIV testing before they could confirm their employment. The majority of these participants were less able to negotiate their decision to disclose in the workplace in a situation where HIV testing is part of their workplace requirements. Those participants consider disclosure due to

the policy of their organisation to conduct various tests including HIV testing for all employees when they are getting or resuming a job. This means that HIV testing is a requirement before an application is successful. It was highlighted that disclosure of status is made because getting the job in such a working organisation is a priority. Participants believed that it would eventually be known when the organisation recommends, they use the workplace clinic centre for a test, or in a situation where the applicant had to pay for the testing, disclosure of status would save them from spending money on HIV testing. However, participants who reported this did not lose their job as a result of disclosure of their status in their workplace.

A participant who was offered a job as a hospital cashier and had lived with HIV for 10 years at the time of the interview highlighted that she was asked to go for HIV testing before her job application could be granted, but she had to disclose her status to save her from going for another test which would have cost her money, as described below:

> '*They tell us to get tested even here before accepting my application, but I told them I have it, so I don't need to do it again. I always tell them I have it, so I don't waste my money again doing the test' (Female, 42, P03).*

A participant, however, said she did not realise she was HIV positive until when she wanted to get a job as a hospital librarian and was asked to go for HIV testing. It was after being tested she realised she was HIV positive, but she appreciated that she was not refused a job because she was HIV positive.

> *'I knew about my status when I wanted to take my job, I came in for medical test… For here, you must get tested before you are offered a job. I found favour, you know, if it is somewhere else, because of that, they may not give you the job again, so I was favoured' (Female, 42, P04).*

Participants were asked if they were sure that their information was secure and would not be handled by an unauthorised person. While a participant was not sure if her information was kept confidential, the other participants believed that it is the management's duty to make staff information confidential. However, she was still not sure if this was the case, as described by both participants;

> 'I can't say that my personal information is secured or not, but it is in the record room' (Female, 42, P03)

> '*Ha! That's their job. If they don't keep our medical record safe, it's up to them but they must maintain it'* (Female, 42, P04).

Participants were also asked if there is any penalty for a breach of confidentiality, for example, any disciplinary measure if anyone is found guilty. Participants reported that working in a hospital setting, an individual is required to keep confidential what is seen as management has the right to dismiss such individual when such confidentiality is not maintained, as described by a participant;

> *'I don't trust anyone…we are in a hospital, not everything you see, you talk about, do you understand…and that it is and that is how it should be. For someone that now says what he is not supposed to say, its left to him or her, and you know there are some things you say and if the management hears about it, they can sack you. If that person put himself in trouble, he should realise is his fault, so let everyone knows what they are doing' (Female, 42, P04).*

Another participant recalled extra measures they took to protect an infected patient in the department where she works. With the authorisation of the head of the department, patient privacy was protected even while accessing treatment, as described below:

'Here, you dear not because Mama must not here such, they will lose their job. I caught someone, some days ago, the Auxiliary, on Friday when we are working, they must not come through this door or pass through this ward; it will result in a problem for them because you know, we keep secret differently. Although it doesn't affect me in any way, I used to tell people' (Female, 32, P06).

This study has found that PLWHA could be in a situation where the disclosure of their HIV status is not negotiable because it is one of the requirements to get a job offer. Although none of the study participants reported that disclosure of their status had cost them their job, they were unsure if their information was kept confidential. Since it is not clear how organisations handled breaches in confidentiality, people living with HIV may face workplace gossip and it can disadvantage their career progress.

Workplace gossip as a determinant to disclose

Workplace gossip or offensive remarks were identified as one of the challenges people living with HIV face in their workplace. Participants worried about who knows about the information and confidentiality surrounding personal information and the likelihood that an unconsented disclosure may happen. Lack of data protection at work may lead to stigma or discrimination, and an emotional reaction such as shame, disgrace, and embarrassment in the workplace. A participant reported that it was a surprise that their medical information could leak from a health professional who happens to be a work colleague and who is expected to know better. This consequently allowed a number of people at his workplace to know about his status and even his church members, as described below:

'My friend who tested me is a medical doctor, I am a nurse by profession, I am a trained nurse, so I managed a hospital in the North. I didn't envisage such a thing would happen. He begins to

tell some of our church members my status. It becomes the talk of the whole hospital, have you heard …he has got infected' (Male, 40, P19).

Meanwhile, a participant did not wait until colleagues started to gossip about her, but voluntarily disclosed to a colleague as she knew that she would still get to know her status as this was no longer a secret in the workplace, as described;

'The sister that came just now used to come here; she didn't know anything because I know mama will not tell her, but I am the one that I used my mouth to tell her. She said what!! You mean… Yes, I am HIV positive, it's not long ago I said it. I know she would know about it somewhere later, but I am the person that informed her personally because I know they will still tell her somehow' (Female, 55, P01).

Some believed that their information was not secured since they had disclosed to a lot of people in the workplace. They did not bother if more colleagues knew about their status and in many cases, colleagues could not confront her to ask about what they had heard. This was easier for a participant as a result of working with other HIV patients, and during the course of her duty used herself to counsel patients about acceptance and treatment procedures.

'It is from one person to another, and they start telling themselves and I don't bother. They can't confront me to ask me' (Female, 55, P01).

'Before they were spreading the news, but the person had lost his/her job now and no longer working here. Humm, so, nobody can accuse me or confront me of such' (Female, 32, P06).

Workplace gossip has caused a lot of damage to participants, such as participants losing their job, feeling insecure in the workplace, change of location, and many times, an emotional reaction such as shame, embarrassment, and suicidal thought. A participant reported that when the news of her HIV status broke at work and colleagues were spreading the news, her relationship with her partner was lost and he had left her since then, as described below:

> *'So, colleagues that know about that' thing' started spreading the news and the guy I was going out with then left me; I didn't see him again. That was why I left that job. Now there is nothing, he has abandoned me, I am pregnant, and I am the one taking care of myself and I am seriously ashamed' (Female, 27, P13).*

A participant also highlighted that workplace gossip had led her to voluntarily leave her job and she could not withstand the shame and disgrace she experienced. It was also reported that due to the spread of the news at her workplace, she had needed to move to another city, losing her livelihood, as described below:

> *'The reason why I left the place is that they don't want me to touch anything or if I use a plate, they may not use it again. So, they believe that may get infected through the plate or clothe when my body touches them. You see that kind of disgrace and stigma. I can't go there again … he came to disgrace me there and people that don't know anything about it were there, so it led to shame for me that's why I moved to XY town' (Female, 27, P13).*

Offensive remarks led to suicidal thoughts as reported by this study participant when she was newly diagnosed:

> *'Also, when my ex-boyfriend came to disgrace me, I felt like poisoning myself because the shame was too much. So, it's as if I should swallow something and die, I had wanted to do it*

because there was a day I wanted to swallow a used battery. I went to buy a cold coke-cola to it with it, and that I should lock myself up and die and they will carry my corpse' (Female, 27, P13).

This participant reported how workplace gossip had cost him lots of damage of losing his job, not able to work in his field of specialisation because of a colleague that breached confidentiality by gossiping about his status among colleagues and clients, as described;

'[Sighed of disappointment] it costs me a lot of things, but I don't know maybe God use it. One, because of my job in the North, maybe I would have managed it and still manage my clinic if the man has not breached the issue of confidentiality, I will still have continued my medical [practice], and then knowing my status, I will take note of general precautions. So, the breach of confidentiality did a lot of things, costs me a lot of things' (Male, 40, P19).

Participants suggested ways to prevent gossip and offensive remarks as a result of living with HIV/AIDS. This includes concealing their status in the workplace. In this situation, there will be a continued social interaction with their colleagues at work, such as eating together, without any form of stigma as described below:

'I did not disclose to avoid talks like this that is why even my bosses at work do use my dishes and cutleries, we do share it and we eat together, I bring food from home and we all eat together' (Female, 35, P17).

Disadvantageous career prospect as a determinant to disclose

Although disclosure may be advantageous, such as receiving support and an assurance of hope to those who are newly diagnosed, disclosure may also put an infected individual in a disadvantageous position in their workplace.

Disclosure has an impact on people living with HIV, as it could lead to the loss of their livelihoods such as personal businesses or jobs. Some participants reported that after people's awareness of their status, they lost their businesses and it was difficult to get another job or pay their staff because the information was out of control. A participant had to leave her job as a result of unconsented disclosure as described below:

> *'I am ashamed. The person that knows about my condition went to my workplace and disgraced me, so that's why I am home now… so it led to shame for me that's why I moved to Y town…That was why I left that job, now there is nothing' (Female, 27, P13).*

A participant also reported that a colleague's awareness of his status made him lose his business and financial income. It was also reported that getting another job was a difficult one as organisations kept rejecting him because of his positive status, and this eventually made him change location with the hope of starting a new life as described below:

> '*.My business crashed down; that added to the sickness as everything begins to crash down… no client, no source of income…I was looking for a job when I came back home with the hope to start a new life, nobody wants to offer me a job. Where I've worked before, if I went there, they say no job…because they have known my status, people I have treated don't want to come to me again… It took me about 4 years before getting a good job again' (Male, 40, P19).*

A participant also reported that disclosure through her involvement in an HIV awareness programme made others aware of her status, although, they did not act as if they knew, as described below:

> *'When the programme started, that was when many people know… Although they may act as if they don't know but they know. It's a lie if we say they don't know but they know' (Female, P01, 55).*

Some participants also perceived that disclosure could be disadvantageous to their career progress. Although they had not experienced it, they were able to share other people's experience of loss of their livelihood because they disclosed their HIV positive status in their workplaces. A participant mentioned that an infected person who was educated was unable to get a job because his/her HIV status was known, as described below:

> *'For people to know that you have this condition, they won't give you job and that shouldn't happen. For someone that has this condition, and educated with a good certificate [grade], they will not offer the person job because of what the person has, and that feeling may cause something. If someone has this condition and has a job, there won't be any problem with finances but if they don't give them a job and they are educated, so what is the gain?' (Female, 42, P03).*

Another participant also reported that there is no benefit of disclosure in the workplace as it could result in loss of job and some unexpected consequences, as described below:

> *'Ha! There is no benefit… The person may lose his/her job. Ha! You can't say that this is what can happen but what I have seen, it can happen that someone loses his job' (Male, 56, P18).*

A participant gave an account of his experience when searching for jobs in social development areas. He assumed disclosure of one's status may attract empathy because of his experience as a human rights activist on HIV, but it resulted in rejection. It was later he realised disclosing his status at every interview was disadvantageous to his career progress which then made him start keeping his status secret, as described below:

> '*There was an instance when I went for an interview, even in this developmental job, sometimes I disclosed to the panellist, just to know, I thought that should enhance the chance to get a job, I thought that would help others but later I discovered that it's a minus for me. I don't know what they are thinking, will this person be fine? Will he not be in and out of the hospital? Will he be able to do the job? And several things, as an activist, will he not be coming here and erhm… So, I discovered that I have been to 1,2,3 interviews and it doesn't help me, later I sat down and I reflected and realised that it's a minus for me so I kept quiet. I didn't disclose to anybody again. It took me about 4 years before getting a good job again' (Male, 40, P19).*

4.2.3 Summary

To sum up, people living with HIV make inferences of others' perception of HIV and this perception translates into the expectations of others' reaction. It also shows that before participants disclosed their status, they found themselves going back and forth in making a decision which may take some time to finalise either to disclose or not. This made some participants believe that when information is out, it cannot be taken back. In a situation where participants have not yet made a decision, they try to find excuses for being absent from work. In some cases, some ran out of excuses. Hence, participants then based their decision on previous relationships with others, their invisible symptoms, their overall health status and disclosure based on association with similar conditions. Meanwhile, some found themselves

in a situation where disclosure of their status was not negotiable, such as to meet their workplace regulations and policies. Hence, they faced the consequences of being disadvantageous to their career progress. The structural representation of the qualitative findings is found in Appendix 2 (d).

The next chapter discusses the findings for both phases within the wider literature and in connection with the conceptual framework of this study.

Chapter Five: Discussion

5.0 Introduction

This chapter begins by presenting a summary of the findings of the two phases of the study, discusses the findings in relation to the conceptual framework, explores the perception of HIV disclosure in the workplace within the wider literature, and provides a summary of the chapter.

5.1 Summary of the findings

This qualitative study explores HIV disclosure among employed people living with HIV/AIDS in Nigeria. The systematic review included 14 studies. The systematic review findings showed that HIV disclosure towards sexual partners or family members were most reported in comparison to disclosure to friends, religious leaders or in the workplace. In the qualitative study, the majority of the participants that disclosed their HIV positive status in the workplace disclosed to their line managers or employers while few others disclosed to their colleagues or healthcare professionals at work. Of the number of people who disclosed their HIV infection in the workplace, less than half of the participants disclosed to their employer because of the issue of trust and data protection, and the fear of others' perception towards them.

Support was received after some participants disclosed their status to both their social and professional networks. It was highlighted that a considerably higher number of participants received financial and psychological support from their partners and close members of the family than from other networks. The qualitative study reported that participants fear the consequences of disclosure in the workplace. Limited access to support was reported among participants who disclosed in the workplace and, as a result, the majority of the participants reported fear of losing their jobs, limited career progression or HIV-related stigma. Despite that, PLWHA received support from their partners after disclosure. However, negative outcomes were reported, such as perceived stigma, blame, rejection by family, abandonment, violence/assault, quarrels, or accusations of infidelity after disclosure of their HIV positive status. Similarly, the majority of those who disclosed in the workplace reported negative

reactions after disclosure, for example, disadvantaging career progress, workplace gossip, the negative perception from others. Meanwhile, for those who did not disclose, they made excuses for their employers in order to attend their medical appointments in the hospital.

In addition, concerns about confidentiality in the workplace were raised among participants in this study. The majority of the participants reported that the information concerning their HIV status could not be reversed as it was known without their consent. Having this in mind, an employed individual decides to manage their status in the workplace either by continuing to make excuses for their health status or disclosing their status when they finally run out of excuses. In other cases, participants based their decision to disclose or not on the closeness they had with others, the level of the visibility of their symptoms or their overall health status, having similar conditions or meeting workplace regulations and policy.

The next section will use the conceptual framework to understand how employees living with HIV/AIDS make decisions relating to the disclosure of their HIV infection in the workplace. The conceptual framework highlights how employees may remain in the position of non-disclosure of their HIV status in the workplace until some incidents triggered their decision to disclose or to remain in the position of non-disclosure. The detailed description of the conceptual framework can be found in section 2.8.2 of the thesis.

5.2 Default Position of Non-disclosure

One of the elements of the conceptual framework is the default position of non-disclosure. The conceptual framework shows that, initially, an employee living with HIV/AIDS remains in a position of not having disclosed their status in the workplace. This position is called a default position of non-disclosure. This does not mean that participants have not disclosed to anyone in their social networks, but participants highlighted they needed a reason to move away from a non-disclosure position in the workplace. Brohan et al. (2012) reported on the waiting period until an employee reaches the point where they feel safe in their position or with their colleagues to disclose their condition. This position can also be referred to as a ‘tipping point’,

where participants reached the stage of making a decision to disclose their status at work. Toth and Dewa (2014) affirmed that maintaining a default position of non-disclosure provides an explanation of the factors that influence non-disclosure in the workplace.

In this study, the perception of others about HIV/AIDS status, perceived stigma, and privacy/confidentiality are part of the reasons why PLWHA maintain their position of non-disclosure of their HIV-positive status in the workplace. Remaining in the default position of non-disclosure ensures that PLWHA maintain their wider identity and prevents it from being linked with their condition. Bond (2010) reported that PLWHA prefer to maintain their wider identity according to their profession (police officer, librarian, cashier, and clerk) or according to their family responsibilities (father, mother, parent, and a child) than to be redefined based on their HIV-positive status at work. The effect of being redefined based on their HIV-positive status is that a work identity will be formed. This work identity can influence categorisation in the workplace. Social identity theory explains categorisation as a way of grouping people that seem similar and identifies differences between groups (Worchel et. al., 1998). It also explains that people tend to categorise themselves into groups - 'us' (in-group - the group they belong to) and 'them' (out-group - the group they do not belong to) - to gain a greater sense of who they are (Briesacher, 2014). In this study, the default position of non-disclosure ensures that participants evaluate their decision to disclose their status carefully and this helps them to maintain their preferred identity before losing it, in case disclosure did not go well. At this stage, there is no going back to a position of non-disclosure. To maintain this wider identity without being defined based on their HIV-positive status, PLWHA continue to conceal their HIV-positive status. Goffman (1968) called this 'Passing'. This concept, passing, is when people successfully conceal their identity of living with a stigmatised health condition. Passing allows an individual to be treated in the same way as anyone else in the workplace (Brohan *et al*., 2012). This means that PLWHA try not to have a conflicting identity at work. Passing is discussed in more detail in section 5.3.3 of this chapter. The majority of the participants in the

qualitative study were found in this position where they prefer to maintain their wider status than to be associated with their HIV condition.

5.2.1 Work performance

This study reported hard work and non-disclosure of HIV positive status. Some participants reported that for as long as they are hard-working, suspicions of their status may be limited. For this reason, PLWHA ensured they are more productive at work and generally try to avoid raising suspicion of their status by their employer/colleagues. This is consistent with the study of Brohan, *et al*. (2012) where employees were conscious not to lose credibility in the eyes of others and so did not embrace disclosure. Loss of credibility comes with lowering one's expectations of the ability to perform well on the job. For instance, an employee preferred to conceal his/her status so that the effort put into the job would not be underrated.

The perception that people with HIV/AIDS are physically 'sick' and unable to perform well at work may influence how employers deal with employees with HIV. To prevent this negative perception, participants have reported that they do extra duties to prove to the employers their capacity to retain their jobs even when facing health challenges. Also, for those who have not disclosed their health status with their employers, they have created the perception of being seen as a 'valued' employee so that there will not be any suspicion that they have HIV. Studies (Bartley, Ferrie & Montgomery, 2000; Aguwa *et al*., 2015) have shown that employees living with HIV/AIDS who have revealed their HIV-positive status in the workplace are likely to lose their jobs. Hence, to prevent the consequences of losing their job, they prefer to keep their HIV status secret at work or overwork themselves to become more valued employees so as to limit any suspicion of their condition. ILO Code of Practice related to HIV/AIDS states that HIV infection should not be a reason for termination of employment, but PLWHA should be 'able to work for as long as they are medically fit to do so in appropriate conditions' (ILO, 2001, p.4).

Hence, participants have reported that without disclosing their HIV status, their employers allow them to take time off work when it is needed due to their previous working performance. This may lead to the conclusion that receiving support from an employer without necessarily disclosing one's HIV status may encourage non-disclosure of HIV status in the workplace.

5.2.2 Perceptions of HIV/AIDS

This study reported that PLWHA maintained their positions of non-disclosure of their HIV positive status as a result of their perceptions and others' perceptions of HIV. Since the onset of HIV, there have been various perceptions of people with HIV. Some of the perceptions include: HIV as a punishment from God, HIV as an **A**merican **I**nfected **D**isease (AIDS), HIV as a death sentence, HIV related to immorality, and HIV as a gay disease (Awofala and Ogundele, 2016; Nasidi and Harry, 2006; Janahi *et al*., 2016; Stolley and Glass, 2009). A qualitative study (Jugdeo, 2009) that explores HIV/AIDS stigma in the workplace among employees living with HIV/AIDS in South Africa also found that people have negative perceptions towards people living with HIV and, as a result, the majority of the people with HIV suffer from isolation and loneliness. Although, there is a change in attitudes, the public specifically in Nigeria continues to hold these negative perceptions (Awofala and Ogundele, 2016). As a result, PLWHA continue to be subjected to hate, blame and isolation (Janahi *et al*., 2016). Meanwhile, this study also reported that PLWHA also believed in these perceptions such as the existence of HIV as a result of sin. This is termed internalised or self-stigma, it "occurs when the person with a stigmatised condition accepts the public stigma to him/herself" (Lyimo *et al*., 2014, p. 98-99). The consequences of internalising this belief may lead to low self-esteem and self-efficacy, less interest in accepting treatment and care, and increased anxiety and hopelessness (Treichler and Lucksted, 2017).

Ajzen (2011) proposed attitude as an important component that contributes to a stronger intention towards behavioural change. A negative attitude/perception is formed when an individual has a negative perception towards the behaviour while a positive attitude towards the behaviour could create a stronger intention towards the behaviour (Ajzen, 2011). To

achieve a desired positive attitude towards disclosure, an individual selected their recipient carefully. This is called *selective disclosure.* Sometimes PLWHA choose certain individuals to whom they disclose their condition, and these trusted individuals often have an understanding of the condition and are willing to support them. These trusted people include those who have been living with the condition for a substantial number of years or health professionals that work for HIV-related organisations and have a sympathetic understanding of HIV. Having access to a support network creates an opportunity for PLWHA to interact with others who have the same condition. Accessing this type of support platform can reduce the emotional distress that comes with HIV diagnosis. In addition, disclosing to a workplace occupational health therapist was also reported to ensure that access to specialist advice would be made easier. This is consistent with a study (Jugdeo, 2009) that reported that employees living with HIV/AIDS prefer to disclose their status to the company nurse or psychologist, while very few can disclose to their line manager and none is happy to disclose to their co-workers.

Choosing someone to disclose to, in the workplace, is guided by what expectation is involved. In the case of disclosure to the company's nurse, there was an expectation that healthcare professionals would be aware of what confidentiality means when dealing with a stigmatised condition such as HIV/AIDS. Frye, *et al*. (2009) reported that disclosing selectively helps to minimise the negative consequences on the identity of an individual infected with HIV. However, a similar study (Arinze-Onyia, Modebe & Aguwa, 2015) conducted in Nigeria reported that a certain number of participants who disclosed to their management reported that the relationship with the management and their work colleagues had not been the same as it was before as the majority experienced negative reactions to disclosure. HIV-related stigma makes individuals feel deviant or different from important others and, as a result, alters their personal identity (Frye *et al*., 2009).

5.2.3 HIV-related stigma

Perceived stigma limits disclosure of HIV-positive status in the workplace among the study participants and maintains their position of non-disclosure of their HIV-positive status. Several

studies (Nattabi *et al.*, 2011; Lyimo *et al*., 2014; Smith, Rossetto & Peterson, 2007; Yuh *et al*., 2014; Wu *et al*., 2015) have documented the effect of perceived stigma on PLWHA which includes delayed access to healthcare, hindrance to adherence to treatment, a reduction in accessing prevention services for people at risk and poor quality of life. According to Tajfel, & Turner (1979), these perceptions have successfully categorised society into 'us', and 'them' and PLWHA fear that they will be identified and categorised differently on the basis of their HIV positive status. Goffman (1963) used the word 'deeply discrediting' when describing stigma. Having a condition that is deeply discrediting could encourage a division or categorisation of people into groups in the society based on the condition they live with. Two similar studies conducted in South Africa and Iran respectively (French *et al*., 2015; Masoudnia, 2016) reported that the community continues to stigmatise and discriminate against PLWHA as a result of fear of transmission or lack of understanding about HIV transmission. These studies also found that the experience of stigma impacts on the decision of the respondents not to consider disclosure of their HIV positive status in their workplace. Disclosure of personal information may require trusting a recipient to keep the information confidential. The next section explains trust and how it is viewed in different circumstances.

5.2.3.1 Trust

Trust is an important determinant of sharing information and developing new relationships with others (Johnson *et al*., 2011). Johnson *et al*. (2011) reported further on the characteristics of trust. These include *asymmetric* – where the trust level is not the same. For instance, an infected person may trust a colleague at work, but that same colleague may not express the same level of trust. The common form of disclosure in this study is disclosure to others who had a similar condition. The outcome of disclosure, in this case, may be beneficial as both parties support each other in the management of the condition. However, participants in this study have also reported the fear of breach of confidentiality as a result of disclosing to a colleague at work.

When trust is *transitive*, an individual who is infected with HIV/AIDS trusted a colleague and the colleague has a friend called C. In this case, an infected person may trust colleague 'C' to a certain extent but if 'C' has a friend called 'D', the trust may not be extended to 'D'. This form of trust shows the ability to choose people who they can trust, who happen to be trusted by other friends. The concept of trusted person is about if a person can keep the personal information confidential. The larger the circle of friends, the less likely personal information is shared within the circle of friends to prevent unconsented sharing of information (Bond, 2010). Sharing their personal concerns is important for PLWHA because it could heal depression/loneliness and other forms of mental illness. At a certain point in the lives of PLWHA, they needed to have trustworthy friends for their psychological well-being. However, considering HIV disclosure as a sensitive decision particularly in Nigeria and due to the stigma associated with the condition, individuals may prefer to maintain their boundaries and keep their information confidential instead of trusting their ability to choose friends who may eventually disclosure their HIV status to others without their consent (Ubesei *et al*., 2016).

Trust may also be *context dependent or context specific*; depending on the context of the information, PLWHA may trust people differently in the workplace. For example, an employee may trust A more than B and so information that will be shared with A may be different to B. In this case, an infected individual may be selective in the disclosure of their status. For instance, sexual partners are the most preferred disclosure recipient before families or friends (Rotzinger *et al*., 2016). Also, an employee may prefer to disclose to his/her colleague than to an employer. More details on selective disclosure were presented earlier in section 5.2.2 of this chapter.

Finally, trust is *subjective.* PLWHA may have a different opinion about trusting an employer. Some may think the employer needs to be aware of their health status to have access to work adjustments while others may think disclosing to an employer may lead to discrimination in the workplace. When most participants reported on disclosing to a 'trusted' person, they perceived that their information will be secure with such 'trusted' person. However, some

participants may remain in the default position of non-disclosure to maintain their confidentiality as they may have not yet found such a trusted individual.

5.2.4 Maintaining confidentiality

To maintain confidentiality, some participants prefer to remain in their position of non-disclosure of their HIV positive status while others, due to their previous experience of breach of confidentiality, limit further HIV disclosure.

Breach of confidentiality and lack of trust in the workplace were reported by participants in the qualitative findings. It was found that employees living with HIV/AIDS cannot be assured that their medical records will be kept confidential and as a result, therefore, the majority of the participants in the qualitative study prefer to conceal their status at work. Arimoto, *et al*. (2013) affirms that the intention to disclose weakens when PLWHA perceive that their health information will not be kept confidential. Bashir (2011) called this a breach of psychological contract when an employer cannot meet its obligation towards an employee. A psychological contract is an employee's 'expectation from an employer and vice versa' (Bashir, 2011, p.157). Breach of confidentiality by an employer or not making an effort to protect an employee's medical records may constitute a breach of psychological contract. This is similar to a study (Weihs & Meyer-Weitz, 2016) carried out among South Africans that affirms that fear regarding lack of confidentiality was reported as the main barrier to HIV disclosure in the workplace. This study reiterates the need to ensure confidentiality in the workplace for those who are willing to disclose their HIV positive status and to promote supportive policies and interventions that protect employees' personal medical records in workplaces.

Participants who are part of a social network in the workplace may find disclosure easier in the workplace than those who have not established one. Awaworyi & Mishra (2017) highlighted that a supportive social group could be advantageous to the management of HIV for a person diagnosed with HIV. Not all participants were able to have access to a support

group in their workplace, while some participants felt that disclosure to colleagues in the workplace who may have similar conditions had supported their adherence to treatment.

5.2.5 Disclosure and association

As trust remains a determinant of HIV disclosure, participants perceived that HIV disclosure in the workplace could be made to colleagues who have similar conditions as them or where there is an intimate relationship. When PLWHA had established their level of closeness with colleagues, they perceived that their personal information would be safe with them.

Disclosure on the basis of association may give hope and assurance to someone who is newly diagnosed with HIV infection and who needs moral support and advice on HIV management. It is interesting that people who have not disclosed to anyone in the workplace among the study participants were willing to disclose to a newly diagnosed person as a duty of care. They highlighted that disclosing to a newly diagnosed person would put them in a position whereby they are able to give advice on the management of HIV, and also share personal information among themselves. Disclosure to other colleagues infected with HIV may make another person feel that his/her secret is secure as they both have a similar condition. Tam *et al*. (2011) affirm that disclosure to newly diagnosed HIV persons is an important way to cope with the distress as a result of being diagnosed with HIV (Tam *et al*., 2011). A study (Musumali, 2012) also reported that disclosure to a work colleague could promote HIV testing in the workplace. A similar study (Brohan *et al.*, 2012) also reported this type of disclosure as a way of educating others about their condition.

Some participants also reported that they could give advice to a newly diagnosed person without disclosing their own status; this could be to protect their personal information in the workplace or because they do not yet trust the person enough to disclose their condition. Brohan, *et al*. (2012) argued that reciprocating the act of disclosure by disclosing to those who disclosed their status strengthens a positive experience of HIV management. Furthermore, disclosure to colleagues who may have a similar condition may support the campaign on HIV

prevention, testing, and adherence to treatment. People who disclose to others with similar conditions act in this capacity because they want to be role models for others (Brohan *et al*., 2012). Tam *et al*., (2011) reported that support given to a newly diagnosed PLWHA could best be provided by a community-based adherence support member of staff. Mostly, community-based adherence support members of staff have similar conditions and can easily relate to the need of other infected people in order to support them with their treatment, while health workers provide additional support (Tam *et al*., 2011; Bond, 2010). Having varieties of approaches to reducing HIV infection and increase adherence has major advantages such as decentralisation of services of care from healthcare professionals in the hospital settings to nonclinical staff and appointment of counsellors who may themselves have HIV (Nachega et al, 2016; Grimwood et al., 2012; Tshuma et al., 2017). Decentralisation of services is feasible, effective and improves good health outcomes of PLWHA. Hence, the use of community-based adherence support members of staff who themselves are HIV patients as reported by the participants expands accessibility and flexibility in supporting the delivery of ART to the community. The 'community-based adherence support members of staff' are a group of individuals who are living with HIV/AIDS but employed and paid by the hospitals to reach out to patients who are diagnosed with HIV/AIDS. This study shows that the support members of staff who were non-clinical staff were recruited to support other newly infected patients to manage their health condition. Their responsibilities include encouraging and giving advice to HIV patients on HIV treatment options, adherence to treatment and the general management of the disease. Sometimes, they provide home visits to patients who are too sick to attend their hospital appointments. Participants in this study reported that it was easier to discuss their HIV status with the community-based adherence support member of staff because they are also living with HIV/AIDS and are in the position to give first-hand information about what it meant to live with HIV/AIDS, especially in a society where HIV patients still experience stigma at all levels. This community support approach to service delivery has continued to be an important and sustainable way that is contributing immensely towards combating HIV epidemic (Nachega et al, 2016).

This study shows that an individual who is in a default position of non-disclosure may consider disclosure as a result of certain incidents that trigger their decision to disclose. For example, an employee living with HIV/AIDS was in a default non-disclosure situation until she found that she needed more time off to access support. So, this incident triggered a decision to disclose. When there are such incidents, PLWHA then may move from a *default non-disclosure* to a position where a certain incident *triggers* disclosure. These incidents include access to support, visibility of symptoms, overall health status, running out of excuses, and workplace regulation and policies.

5.3 The triggering incident

The qualitative findings of this research highlighted that certain incidents could trigger disclosure in the workplace even when an employee has determined not to disclose their HIV positive status to anyone in the workplace. This may also be referred to as a 'tipping point' where certain incidents triggered disclosure and there is no turning back when the decision is eventually made. This is similar to the study (Toth and Dewa, 2014) conducted among employees diagnosed with mental illness as they reported that they were not considering disclosure in their workplace until struggling with work or sharing with a colleague about their personal information triggers their decision to disclose at work. In this study, there is a re-assessment of the decision to disclose or not in the workplace. The triggering incidents reported by participants in this study include running out of excuses, workplace requirement, and policy, support, overall health status, or visibility of symptoms. When any of these triggering incidents happened, the decision to disclose was re-assessed considering the risk and the benefit of disclosure. Hence, a decision to disclose or not will be made. The triggering incidents are important in informing the decision-making of PLWHA because they are able to determine how employees living with HIV/AIDS make a decision to disclose their HIV positive status to their employers or their colleagues in the workplace in order to get a work adjustment.

Reasonable adjustments are expected to be provided by an employer to assist an employee living with a disability to meet his/her work responsibility (Conyers and Boomer, 2005). The

common job adjustments requested by employees with HIV include permission to meet doctor's appointments, flexible work pattern, shortening work days. These adjustments may not be provided to an employee who needs them if disclosure is not made. These findings highlighted that some participants do not disclose their HIV status but prefer to make excuses in order to access workplace adjustment. Meanwhile, keeping a secret of their HIV status may result in difficulty in taking time off work to go for medical checks.

5.3.1 Absenteeism

Regular doctor's visits during weekdays make participants worry about their regular absence from work. UNAIDS (2000) and Rosen, *et al*. (2003) highlighted that a continuous absence from work may result in low productivity of organisations. Absenteeism hence becomes costly for the organisation where the employee's role is a significant one in the organisation and cannot be replaced easily (UNAIDS, 2000). Business enterprises also reported that employing PLWHA increases organisation running costs and causes low productivity as a result of consistent absence from work, unexpected illness or sudden death (Rosen *et al*., 2003). In situations where participants tried to avoid consistent absence from work, they result in making excuses to attend their hospital appointments.

Making excuses

Participants reported that they have to provide some excuses in order to take time off work such as family responsibility (e.g picking a child up from school) or general health check-up without being specific. Jugdeo (2009) reported that adherence to treatment and meeting doctor's appointments were essential in the management of HIV/AIDS for the quality of life. For this reason, participants reported that meeting doctor's appointments are important in the management of their illness. However, they struggled to disclose their status to their employer to take time off work to visit the doctor.

These excuses involved participants falsely disclosing a previously known illness different from HIV such as asthma, malaria or cold. Many participants in this study believed that a false

disclosure of their status to their employers, especially when not sure of the consequences, could be used to protect them against any form of stigma at work. However, other participants made excuses for their inconsistencies at work or their frequent hospital visits. Serovich & Mosack (2003) reported that PLWHA who took the decision not to disclose their HIV status or falsely disclosed their status did so because of the shame of having HIV. Participants in this study also felt shameful because of the way they contracted HIV, their inability to prevent the transmission, or having the disease itself. It can be concluded that when people with HIV feel shameful of their condition, this may increase the rate of non-disclosure of HIV in the workplace. Non-disclosure or false disclosure of HIV status makes PLWHA 'carry an additional burden of feeling shameful about their HIV positive status' as they continue to live secretly with their status (Serovich & Mosack, 2003, p.77). To maintain non-disclosure or false disclosure of their condition, some participants made excuses for their inconsistencies at work or their frequent hospital visit.

PLWHA make excuses to protect their identity in circumstances where it is more likely to be stigmatised. These excuses were planned to exhibit the kind of characteristics that made them look genuine, acceptable, consistent (sometimes, not consistent to avoid suspicion), convincing, empathetic, unsuspicious, and that could be justified. Excuses that are continuously generated and meeting individual needs limit disclosure of HIV-positive status in the workplace but promote non-disclosure among employees living with a positive status (Kaler, Angotti & Ramaiya, 2016). Meanwhile, Bond (2010) reported that non-disclosure of HIV in the workplace among PLWHA increases the stress level, transmission of the virus or limits better healthcare support. When PLWHA find it difficult to adhere to treatment, and they run out of providing excuses for their absence from work, they may consider disclosure of their HIV positive.

Flexibility in accessing treatment may reduce possible involuntary disclosure in the workplace. The majority of the participants in this study who work on weekdays find it difficult to attend their monthly routine check as the facility can only be accessed on weekdays. For such

affected employees, they devise possible ways to request a time off work to attend their hospital appointments. Workplace conditions such as stress, hazardous and inflexible work schedules can increase health deterioration of the individuals. Therefore, employers who have employees with chronic conditions such as HIV should provide some flexibility in their working conditions to help these individuals in attending their treatments. The majority of participants in this study have dependants that included children, grandchildren, partners, grandparents or other relatives. Having some flexibility in the workplace would increase better management of their situations. This is consistent with a study (Aguwa *et al*., 2015) conducted in Nigeria where the majority of the employees living with HIV/AIDS reported that accessing treatment was difficult for PLWHA and that employers find it difficult to grant a request or give a day off to their workers. Brohan, *et al*. (2012) affirm that disclosure is connected to gaining adjustment in the workplace but those that do not need adjustment are not likely to consider disclosure. However, for those who needed some adjustments, employers should be knowledgeable about their needs and how it can be met. In the UK, the Equality Act (2010) provides a legal protection for workers with chronic disease. It requires that employers should provide 'reasonable adjustments' so that the affected employees would be able to manage their condition together with their jobs. The reasonable adjustment includes adjustments to employees' workspace, flexible working hours and reasonable breaks in between, providing equipment needed to help productivity, adjusting performance target and readjusting responsibilities within the team (NHS Choices, 2018). These adjustments can protect employees from being treated less favourably because of their conditions. Meanwhile, Nigeria also introduced an act called HIV/AIDS Act 2014 that made it illegal to discriminate against people based on their HIV status (UNAIDS, 2015). This also prohibits an illegal act of an employer or an organisation to require HIV test as a condition for applying for a job or accessing services. Considering that some participants reported that disclosure of HIV status is a requirement for an employment, employers' awareness and implementation of the law should be enforced. Therefore, supporting employees with HIV in the workplace through clear policies that provide workplace flexibility and adjustment would increase productivity, reduce

absenteeism, encourage good performance and the overall improvement of the quality of their lives.

The consequences of consistent absence from work were reported in this study. Some participants reported that consistently requesting hospital visits or finding excuses for not coming to work may put an individual's job at risk and eventually lead to loss of a job. Bartley, Ferrie, and Montgomery (2000) researched the link between unemployment and illness and found that, although physical health does not necessarily decline when an individual faces unemployment, a person is more likely to lose his/her job and find it difficult to regain another job because of their illness. Nevertheless, adherence to HIV treatment is important in order to continue to be a productive member of society (Conyers and Boomer, 2005).

Medication intake at work

The improvement in health depends on strict adherence to medication, whereas non-adherence could put an individual at risk of developing viral resistance (Cama *et al*., 2015). Hence, PLWHA took adherence to medication seriously but still raised the concern of how this can be taken in the workplace without an involuntary HIV disclosure. PLWHA could give excuses that seem acceptable, while some, to avoid this, do not take their medication within working hours to avoid suspicion of their status. Common excuses made include taking medication for a less stigmatised condition or lying about a previous illness known to them which requires a long-term medical treatment. Taking medication in the presence of colleagues was reported to bring suspicion and raise questions as to why the medication was being taken. This is consistent with similar studies (Tam *et al*., 2011; Cama *et al*., 2015) where PLWHA raised the concern that taking medication in public is more likely to increase treatment-related stigma. However, a study (Degroote *et al*., 2014) that investigated people living with HIV/AIDS in the workplace reported that few of the study participants took medication in the workplace and those who took medication during work time reported little or no negative response from their work colleagues.

Participants reported that taking medication at work triggers the disclosure of their HIV positive status in the workplace. Participants whose time for their medication intake falls within working hours may eventually disclose to their employers, but in situations where they prefer not to disclose their status, it may result in poor adherence to the treatment. Arinze-Onyia, Modebe & Aguwa (2015) reported that poor adherence to medication has far-reaching implications for the overall patient's management of their condition. Also, post-disclosure consequences affect patients' confidence to access HIV treatment and HIV services (Cama *et al*., 2015).

The qualitative findings of this study show that HIV medications were recognised by others when they took their medications, which sparked some reactions, such as being suspicious of their condition or becoming curious about why they were on medication. In this case, many intended to store their medication in an unrecognised package so that other people would not notice it. This type of decision increases their confidence to adhere to medication even in a working environment without the pressure to disclose their HIV status. This is consistent with a study (Tam *et al*., 2011) that reported that adherence to treatment and concealing HIV positive status could be done by disguising ART medication, lying about the type of medication taken or delaying taking medication until it can be done privately. When there are concerns about being able to take one's medication freely, adherence to treatment may become difficult. However, patients' confidence can be improved with a non-threatening environment that encourages access to HIV treatment and HIV services.

Meanwhile, the use of medication in the workplace may not always lead to negative reactions from their colleagues as some participants reported that other colleagues also use medication for other conditions. In this type of situation where colleagues at work used medication for various conditions, employees infected with HIV/AIDS worried less about disclosure of their HIV positive status in the workplace. Participants who did not disclose their HIV status in the workplace reported that living with HIV/AIDS for a number of years; or attending a support group assisted them in deciding whether to disclose or not in the workplace. A support group could be a patient-led group created to stand in solidarity and support for each other in the

overall management of HIV. This is consistent with Aguwa, *et al*. (2015) as they reported that an individual infected with HIV who joins a support group could potentially learn strategies to deal with concerns surrounding living with HIV/AIDS and disclosure. The roles of support groups for people living with HIV/AIDS have been documented in the literature (Olley, 2007; Bateganya *et al.,* 2015) as an intervention that addresses the psychosocial needs of PLWHA. Olley (2007), who investigated the role of support groups among patients living with HIV/AIDS in Nigeria, reported that belonging to a support group increases the knowledge of patients about HIV-related issues and improves the positive attitudes about living with the condition. Similarly, Bateganya, *et al.* (2015) found that support groups serve as an intervention that impacts on the morbidity and the quality of life of PLWHA; they also provide support in terms of disclosure. This is reported among some participants where they highlighted that joining a support group had assisted them to evaluate their decision to disclose their HIV status in the workplace.

5.3.2 Workplace requirement and policy

This study reported that a requirement to disclose in the workplace could influence the decision to disclose. Disclosing one's HIV status by meeting workplace regulations and policy was found in this study as another way PLWHA disclosed in their workplace. Some participants found themselves in a situation where they needed to disclose their HIV status or go for HIV testing before they can confirm their employment. Such people include those who work in health settings. This is similar to a study (Arinze-Onyia, Modebe & Aguwa, 2015) in Nigeria that reported that some PLWHA were forced by their employers to do an HIV test. In this case, PLWHA were less able to negotiate their decision to disclose in the workplace as HIV testing was part of their workplace requirement. The Nigerian Labour Congress HIV policy identifies the rights and protection of PLWHA not to test for HIV as a requirement for gaining employment, although this is not enforced (Arinze-Onyia, Modebe & Aguwa, 2015). However, a similar study conducted in Nigeria (Aguwa *et al*., 2015) argued that HIV testing may be

compulsory before or during employment for some types of job, but an employee's contract should not be terminated as a result of their HIV positive status.

In sub-Saharan Africa, where HIV is a public health concern, there are 26 HIV-specific laws that protect the rights of PLWHA (Eba, 2015). Evidence of all 26 HIV-specific laws was not available as stated by the author (Eba, 2015), however, these laws were reported by the stakeholders interested in ensuring PLWHA are free from all forms of discriminations. The stakeholders include the International Covenant on Civil and Political Rights (ICCPR), African Charter, International Labour Organisation (ILO), and the International Covenant on Economic, Social and Cultural Rights (ICESCR). These laws serve as a 'structural tool' to assists states to respond to individual behaviour that is HIV-related, and the difficulties encountered when dealing with these challenges (Eba, 2015; ILO, 2014). Key issues addressed in these laws include non-discrimination, employment, HIV testing and counselling, and criminalisation of HIV non-disclosure, exposure, and transmission (Eba, 2015).

Before 2005 in sub-Saharan Africa, only three countries had adopted these laws: they are Angola, Burundi, and Equatorial Guinea. As of 2015, more than 27 countries have adopted HIV-specific laws as opposed to HIV-related legislation which includes Angola, Benin, Burundi, Uganda, and Congo. See Appendix 15 for the list of all the 27 countries out of 45 that have adopted these laws. Meanwhile, evidence[7] has also shown that in 2015, Nigeria also adopted some of the ILO recommendations which provided that PLWHA should not be discriminated against based on their HIV status. The most relevant law to this study is the HIV employment law. In the aspect of employment, work-related policies were set out to protect the rights of PLWHA. These include non-discrimination in employment; preventing HIV testing as a condition for employment; privacy and confidentiality in the workplace; reasonable accommodation/adjustment for HIV-positive workers if needed; access to post-exposure

[7] Link to the evidence of the act signed by the Federal Republic of Nigeria (2015): https://www.ilo.org/wcmsp5/groups/public/---ed_protect/---protrav/---ilo_aids/documents/legaldocument/wcms_444112.pdf

prophylaxis in case of occupation exposure and compensation in case of occupational HIV infection; the requirement for HIV policies and programmes in the workplace (ILO, 2014). However, the concern is that not all countries in sub-Saharan Africa adopted these and it is not binding (Eba, 2015). Some countries have incorporated vague anti-discriminatory laws, such as Burkina Faso, Tanzania, and Burundi. No country in sub-Saharan African has adopted the full HIV employment law. This reflects why PLWHA are still faced with the fear of discrimination in the workplace. As some participants in this study reported that disclosure of their HIV status is a requirement for a successful employment, they cannot guarantee the privacy and confidentiality of their personal information. Therefore, public health should continue to advocate for government and employers to be proactive in implementing ILO policies and guidelines to protect PLWHA in the workplace.

Although findings also showed that some participants were unable to negotiate the decision to disclose their HIV positive status in the workplace as it was one of the requirements to get a job offer, none of them reported that disclosure of their status in the workplace had made them lose the opportunity to have a job. This is similar to a study (Degroote *et al*., 2014) that showed that disclosure in the workplace does not affect the employment of an employee with HIV. However, contradicting views were reported in a study conducted in Nigeria (Arinze-Onyia, Modebe & Aguwa, 2015) where disclosure in the workplace led to the loss of job or discrimination in the workplace. These show that the outcome of disclosure could vary among individuals depending on organisations or the management they work with. Although participants could not guarantee that their medical record would be kept confidential, they maintained that there is a disciplinary measure against anyone found guilty of revealing others' health information as working in hospital settings requires being able to keep information of others confidential. Eba (2015) proposed that in organisations where disclosure is compulsory, workers' health information should be kept confidential. Only five countries in sub-Saharan Africa explicitly address the protection of medical data of PLWHA in the workplace (Eba, 2015). Non-discriminatory policies, either implemented as a legal requirement or internally

accepted within an organisation, should reflect protecting PLWHA against any form of discrimination in the workplace (Clair, Beatty and Maclean, 2005). The Nigeria Ministry of Labour and Productivity (2013) announced in a national HIV/AIDS policy that all organisations must be proactive in tackling the burden of stigma and discrimination against employees infected with or affected by HIV/AIDS by implementing successful HIV and AIDS policies and programmes as a first step to overcoming HIV burden.

5.3.3 The invisible condition

As mentioned in section 2.5.2 of this thesis, people's illness can be perceived in two ways: these include visible illness and invisible/concealable illness (Jans, Kaye, and Jones, 2012; Saal, Martinez & Smith, 2015). Visible illnesses are symptoms that are physically clear to others (Lively & Smith, 2010). An invisible illness becomes known or is apparent when an individual discloses to others (Saal, Martinez & Smith, 2015). Visible characteristics that define people 's identities are 'the traits that can be observed by seeing or speaking with someone, whereas the invisible identity cannot be discerned' (Sage & Joseph, 2015, p. 22). HIV is an illness that can be visible or invisible depending on the progress of the disease. HIV progresses as the immune system becomes weaker and susceptible to infections, resulting in an advanced stage of HIV (Katherine, 2000). HIV symptoms then become visible at the early stage of diagnosis or at an advanced stage called AIDS.

This study reported that visible symptoms of HIV infection trigger the decision to disclose in the workplace. At this stage, an ill person loses control of how the body functions (Fraser & Greco, 2005). Meanwhile, advances in HIV treatment, its availability, and adherence to treatment make HIV an invisible condition until it progresses to a stage where immune systems become weaker or when complications as a result of the infection arise (Annequin et al., 2016). As a result of its invisibility, the physical well-being of PLWHA does not deteriorate (Tsai *et al*., 2013). Also, the relative invisibility of HIV means that it is often unobservable to potential employers and so job applicants and employees with HIV/AIDS have a level of choice regarding if and when to disclose their HIV-positive status (Brohan *et al*., 2012).

Clair, Beatty & Maclean (2005) reported that PLWHA based their decision to start work after recovery on their appearance and fitness to work. An individual with an invisible condition such as HIV has the choice to either disclose or not in their workplace. It can be inferred that having an invisible condition such as HIV/AIDS helps PLWHA to control the information that is shared. This is because the visibility of a stigmatised condition is a key factor in defining an individual's social identity (Brohan *et al*., 2012). As mentioned earlier in this chapter, passing is a concept used by Goffman (1968) to describe how information about a stigmatised condition can be controlled. For instance, HIV-related stigmatisation can be controlled by not disclosing one's condition to others or by disclosing to a selected few. However, when conditions are visible, the ability to 'pass' is difficult (Goffman, 1968).

HIV is a concealable illness when its symptoms are hidden due to adherence to treatment (Annequin *et al*., 2016). Its visibility as a result of health deterioration could trigger disclosure (Annequin *et al*., 2016). Brohan *et al*. (2012) called this type of disclosure 'inadvertent' disclosure. However, the invisible attributes of HIV could limit disclosure (Kaler, Angotti & Ramaiya, 2016). This can be explained using the Disease Progression Theory detailed in section 2.8.1 of this thesis. It establishes the need to disclose based on the progression of the disease (Kalichman, 1995) when the condition can no longer be kept a secret. Frequent admission to hospital or a decline in health might prompt disclosure (Serovich, 2001).

In this study, the invisibility of symptoms was largely based on the participants' adherence to treatment. They reported that adherence to their medication as prescribed would contribute to their general health and a good quality of life. Furthermore, Kaler, Angotti & Ramaiya (2016) argued that since the availability or accessibility of ART to PLWHA makes HIV an invisible condition, fewer people will be willing to disclose their status. In addition, an invisible symptom may reduce the chances of accessing support that could have an implication on the quality of life of PLWHA (Brennan & Creaven, 2016). For instance, an employee whose HIV status is not known to others may not consider seeking support from an employer so that they can continue to conceal information about his/her HIV status. Nevertheless, invisible symptoms

could be beneficial in terms of planning well before a decision to disclose is made but could be disadvantageous if the infected individual stops adhering to treatment (Clair, Beatty & Maclean, 2005). On the part of an infected person, there is an advantage of not having a visible symptom as it gives the confidence to give advice and counsel to newly diagnosed HIV persons who believe HIV infection means an end to their lives.

As HIV progresses into AIDS, poor health and opportunistic infection can be reasons for disclosing in the workplace (Conyers and Boomer, 2005). Opportunistic infections (OIs) are infections that frequently occur among individuals with weakened immune systems, including people living with HIV/AIDS (Centres for Disease Control and Prevention, 2015). Not having a visible symptom is not enough but having an overall good health status could help PLWHA to manage their disclosure in the workplace. Recovering after diagnosis could reduce the chances of disclosure in the workplace as reflected in this study, although some participants might consider disclosure in the future.

5.4 Post-disclosure

Participants disclosed in the workplace after assessing the possible risk or benefit of disclosure to their employer or a colleague at work. Serovich (2001) reported that if the benefit of HIV disclosure outweighs the cost, the disclosure is likely to occur. However, if the cost of HIV disclosure outweighs the benefit, disclosure may not be considered except where HIV symptoms become visible as explained earlier in this thesis. In addition, the study identified that PLWHA access counselling services in the best way to deal with the disclosure in the workplace and seek advice on the post-disclosure consequences. Some participants reported their actual experience after disclosing at work.

The post-disclosure consequences could be both positive and negative as reported in the systematic review findings phase of this study. Disclosure to sexual partners mostly reports supportive reactions such as financial, social, and psychological. However, negative reactions such as sex deprivation, blame, rejection, violence/assault, stigma/discrimination, the

accusation of infidelity, divorce were identified (Sagay *et al*., 2006; Ezegwui *et al*., 2009; Okareh *et al*., 2013; Adekanle *et al*., 2015). In addition, this qualitative study reported that PLWHA who disclosed their status in the workplace at some point in their lives found that their personal information was revealed without their consent. An unconsented HIV disclosure of status could also lead to gossip and offensive remarks, disadvantaging career progress, and emotional distress. These will be discussed in detail in the following sections.

5.4.1 Gossip and offensive remarks

Gossip is a way of talking about a particular person or situation which cannot be openly discussed (McNeill, 2009). This study found that workplace gossip is one of the challenges PLWHA face in their workplace. To stop workplace gossip, some participants voluntarily disclosed to a colleague to prevent further gossip among their colleagues. This is similar to a study in Zambia (Musumali, 2012) where PLWHA disclosed their HIV positive status because they wanted to prevent gossip among their colleagues. Passing offensive remarks or gossiping about an infected person is commonly reported in studies on HIV disclosure in the workplace (Musumali, 2012; Arinze-Onyia, Modebe & Aguwa, 2015). Consistent exposure to such remarks in the workplace could reduce social interaction but raises emotional implications for an employee who is infected with HIV/AIDS. This could also impact on the confidence to request work adjustment as mentioned earlier in this chapter.

Musumali (2012) argued that disclosure does not necessarily lead to gossip in the workplace as support may be received from the management when disclosure is made. Musumali (2012) went further to explain that the management may appreciate the confidence of an employee living with HIV/AIDS to disclose in the workplace given the sensitivity surrounding HIV and disclosure. To prevent gossip, non-disclosure of status was preferred by some participants so as to maintain professional interaction in the workplace. Participants reported that the implementation of an anti-discrimination law to protect people living with HIV could encourage disclosure in the workplace. In the process of reporting an incidence of discrimination, the

victim may face further stigma as more people may be aware of the HIV condition after making a report (Mayfield *et al*., 2008).

5.4.2 Disadvantage to career progress

This study reported that the career of PLWHA might be affected after a disclosure is made in the workplace. Work is primarily a means of meeting an individual's economic and financial needs (Arinze-Onyia, Modebe & Aguwa, 2015). In the Nigerian context, people rely on job opportunities to meet their financial needs because there is no access to social welfare. Other alternatives whereby people meet their financial obligations are to establish a small-scale business as a means to support their households and other dependants. The majority of the participants highlighted that work opportunities remain the only primary means of survival, financial independence and for meeting socio-economic needs. This study found that PLWHA faced the loss of their livelihoods such as personal businesses or jobs as a result of disclosure in the workplace and it was challenging to get back into employment. This is consistent with a similar study (Arinze-Onyia, Modebe & Aguwa, 2015) in Nigeria where PLWHA lost their job or changed their work pattern after they disclosed their HIV-positive status in their workplace. This study also showed that some participants who are working with HIV campaign organisations, whose work is to create awareness on HIV testing, were unable to get accommodation because they disclosed their HIV positive status during one of their campaigns. Evidence (Aidala *et al*., 2016) has shown that the housing crisis is one of the challenges of PLWHA. Housing is not just a physical shelter but a place where personal, social, mental and economic lives of people come together (Aidala *et al*., 2016). A lack of shelter may mean that the physical and psychosocial well-being of PLWHA will continue to put PLWHA under stress with low quality of health and wellbeing. The lack of stable housing continues to form a barrier to maintaining employment and consequently increased poor health, loss of income and stigma (Aidala *et al*., 2016).

Aguwa *et al*. (2015) mentioned that employed PLWHA feared that they might lose their job or their source of income due to their HIV positive status. Loss of job could result in a low living

standard and hence increase the rate of poverty in society (Bartley, Ferrie & Montgomery, 2000). Since HIV continues to mostly affect people who are of working age, more working-age people will continue to be unemployed due to the consequences as a result of their HIV disclosure in the workplace (Annequin *et al*., 2016). Some participants reported a loss of a job as a result of disclosing at work, while others reported an inability to make further progress in their career as a result of disclosure in the workplace.

The rate of unemployment continues to increase for PLWHA who are willing to enter, re-enter and remain in the labour market, and they continue to be excluded from the labour market as a result of HIV (Annequin *et al*., 2016). About half of the people infected with HIV lost their job within one year as a result of HIV infection (Annequin *et al*., 2016). This shows that the risk of becoming unemployed is at its highest shortly after becoming infected with the disease. Some participants in this study reported a similar experience. These include withdrawal from their job because of the fear of stigma, offensive remarks or due to frailty/ill health after diagnosis as discussed earlier in this chapter. Unemployment was found to be a key indicator in the context of chronic illnesses affecting young working-age people (Annequin *et al*., 2016). This is particularly true in the case of HIV/AIDS, a condition that is less visible and 'manageable' and has been redefined from a terminal to a chronic condition due to medical advances but that continues to have a socioeconomic impact on the world (Conyers *et al*., 2017; Annequin *et al*., 2016).

Conyers, *et al*. (2017) highlighted an individual's health outcomes can be determined by social factors. Some of the social factors related to HIV/AIDS include socioeconomic status or poverty. There is a relationship between socioeconomic inequality and health outcomes. The impact of socioeconomic inequality is huge; part of which causes poor health in society. Poor health outcomes are associated with low income or unemployment regardless of gender (Robertson, 2014; Rozer & Volker, 2015). Bartley, Ferrie & Montgomery (2006) also highlighted the relationship between socioeconomic inequality and poor health outcomes and argued that poverty has implications for health outcomes. For instance, an infected person

who is unemployed and has no source of income may find it difficult to care for him/herself and as a result, may lead to a poor or deteriorating health outcome. This demonstrates what the experience of PLWHA might be if they lose their job as a result of disclosure. Studies (Annequin *et al*., 2016; Conyers and Boomer, 2005) have shown that being diagnosed with HIV increases poor health and consequently influences the rate of unemployment.

The labour market plays a role in determining the health outcomes of PLWHA. This includes providing a favourable environment where people living with chronic conditions such as HIV can continue to live a productive life devoid of a threatening working environment where employees face HIV-related stigma as a result of their conditions. Meanwhile, the benefits of employment for PLWHA are numerous. Conyers, *et al*. (2017) and Bartley, Ferrie & Montgomery (2006) highlighted that lack of employment or unstable employment can lead to psychological problems for PLWHA such as stress, depression and suicidal thoughts. However, having a stable job improves self-esteem, social functioning and the ability to deal with life challenges. Employment also contributes to skills acquisition, social networks, secure identity and the quality of life for PLWHA (Bartley, Ferrie & Montgomery, 2006).

One of the reasons why PLWHA experienced loss of job or discrimination in the workplace as highlighted in this study is their employer's negative attitude or perception towards recruiting PLWHA. A study (Lim and Loo, 2000) among employers and human resource managers conducted in relation to their opinions on recruiting PLWHA reported that recruiting PLWHA may have adverse consequences on the productivity of the organisation. Similarly, other studies (Conyers and Boomer, 2005; Buck *et al*., 2011) reported that many employers refused to employ PLWHA on the basis of their status, as employing them may have an effect on the work productivity or the company's expenditure. Loss of job on the basis of having a condition such as HIV/AIDS demonstrated an adverse reaction to the disclosure of HIV status in the workplace and reflected the reason for the low rate of disclosure in the workplace (Conyers and Boomer, 2005). Meanwhile, a similar study (Degroote *et al*., 2014) that investigated disclosure in the workplace found that PLWHA did not lose their jobs, but they reported

receiving empathy after a disclosure was made in their workplace. This study also reported that PLWHA felt a psychological satisfaction when they disclose at work. Having a ‘peace of mind’ to take their medications or to ask for a time off work from their employers gives an emotional support to adhere to treatment. This is consistent with a similar study (Musumali, 2012) that reported that HIV disclosure in the workplace eases the emotional burden of PLWHA.

To sum up, this study shows that PLWHA used different approaches to make a decision on whether to disclose their status in the workplace or not. Although the disclosure is required if support needs to be sought from an employer, PLWHA may not disclose their status and may still have access to support as a result of disclosing less stigmatised conditions to their employers. In an organisation where HIV disclosure is not a requirement for a successful job application, the disclosure of HIV infection by an employee may not be necessary until complications due to the disease arise. Whether employees disclosed their HIV infection or not in the workplace, there will be consequences.

5.5 Summary

This chapter discussed the findings of this study within the existing literature. It outlined that PLWHA may be at a default position of non-disclosure in the workplace until incidents such as running out of excuses, workplace regulation/policies, or decline in overall health influence disclosure of HIV-positive status. It then highlighted planning disclosure based on the potential risk or benefit of post-disclosure, as trust plays a significant role in the decision making. Also, the study reveals the importance of living with an invisible condition and its influence on the timing of disclosure.

The next chapter is the concluding chapter.

Chapter Six: Conclusion

HIV/AIDS is a socioeconomic condition because it affects a higher percentage of people who are sexually active and are economically viable globally (Umesh *et al*, 2013; Aguwa *et al*., 2015). Advances in HIV treatment have improved the prognosis for people living with HIV/AIDS (PLWHA) and their overall health. As a result, PLWHA can be employed for longer and whilst they manage their condition. There is a range of evidence (Dean, 2014; Odimegwu, Adedini & Ononokpono, 2013; Senyalo, Maja & Ramukumba, 2015) that people with infectious diseases, and especially HIV/AIDS, are being stigmatised. Stigmatisation or the fear of being stigmatised, can affect the ways or whether the affected person would disclose their disease to their social and professional networks. This research explored HIV disclosure in the workplace among PLWHA in Nigeria.

As has been explored in the previous chapters (see section 2.2.3), Nigeria remains one of the countries with the highest prevalence of people living with HIV/AIDS including children. Nigeria is in the second position of countries in Sub-Saharan Africa with the highest prevalence of PLWHA after South-Africa. Also, Nigeria is the third in the world with more than 3 million and

more than 200,000 new HIV infections, and about 160,000 AIDS-related deaths currently recorded (Awofala and Ogundele, 2016). Although the rate of new infections continues to decrease due to the advancement in HIV treatment and its access to the treatment, HIV-related stigma still remains a concern in Nigeria due to the misconceptions associated with the disease. These misconceptions include HIV as a punishment from God, HIV as an **A**merican **I**nfected **D**isease (AIDS), HIV as a death sentence, HIV related to immorality, and HIV as a gay disease (Awofala and Ogundele, 2016; Nasidi and Harry, 2006). These misconceptions may cause many PLWHA to fear the consequences of disclosing their status to others, particularly in the workplace. When PLWHA do not disclose their status in the workplace, they may not be able to have access to workplace adjustments that could support the management of their condition in the workplace. The workplace adjustments include the provision of equipment, modification of work schedule, permission to meet doctor's appointments, flexible work patterns, shortening work days. This research explores the perception of PLWHA in disclosing their HIV-positive status in the workplace by conducting two phases of the study: the systematic review to collect and synthesise evidence on HIV disclosure, and a qualitative approach to explore the perception of PLWHA in disclosing their status in the workplace using a face-to-face interview.

This study contributes to an in-depth understanding of the perception of HIV disclosure of an employee who may consider disclosure or non-disclosure of HIV/AIDS in the workplace. It also shows the implications of disclosure or non-disclosure for the way PLWHA adhere to treatment and meet workplace responsibilities.

PLWHA put trust and support at the centre of their decision-making regarding the disclosure of their HIV positive status in the workplace. Based on the study findings, HIV disclosure is a gradual process that starts usually with close networks such as sexual partners, family members and friends, but the decision to disclose to a close network is on the basis of the support needed at the time of diagnosis. PLWHA depend on their family members to support them, especially at the early stage of diagnosis. This could be one of the reasons why

disclosure among close family members is more common for PLWHA than disclosure in the workplace. Bond (2010) supported the idea that disclosure in the workplace is not common because PLWHA preferred to disclose to a limited number of people to maintain their privacy (Bond, 2010). In maintaining their privacy, many affected people limit the disclosure of their HIV-positive status to close social networks of friends/ family, and sometimes to people who have a similar health condition. This act of hiding the HIV condition is often used to reduce the negative consequences they might face as a result of their disclosure of HIV status.

In this study, trust is central to the disclosure of HIV positive status in the workplace. It becomes a determinant of sharing personal information with someone that is perceived to be trustworthy. The issue of trust brings the question of how they assess someone that is trustworthy. Some participants reported that their previous dealings with an individual or how previous situations were handled by the individual was mostly used to measure if someone could be trusted with their personal information. Other participants reported that the length of their relationship with an individual could be used in measuring what a potential recipient could do when they eventually know about their HIV status. Meanwhile, the majority of the participants in this study believed that people with similar conditions such as HIV can be trusted with their personal information because they can keep each other's secret, and with that, they do not have anything to lose disclosing to someone having a similar condition. In this study, participants referred to people having similar conditions as 'insiders' because they understand the sensitivity with living with HIV/AIDS in Nigeria and the importance of limiting the disclosure of their condition.

The word 'insider' here is different from the role of the researcher as an 'insider' or outsider as explained in section 3.2.10. While the latter talks about the role of a researcher in the overall research process and the impact it has on the data collection, the former reported on the decision by PLWHA to disclose their HIV-positive status to people living with the similar condition.

In disclosing HIV status in the workplace, the main concern of PLWHA is about confidentiality in respect of keeping their personal information safe at work while they have less concern about sharing their personal information with their families and friends. Confidentiality of personal information is important when dealing with sensitive information. For an individual who provided the information, to have an assurance of their confidentiality, organisations need to be transparent about what data was collected, the purpose of the data collection, what it will be used for, how long it is going to be kept for and who has access to the data, according to the UK's 1998 Data Protection Act: a guiding set of principles to follow in storing personal data (Data Protection, 2015). When employees have no information about how their data will be protected, they have less confidence in the ability of such an organisation to maintain the confidentiality of their personal information. The consequences of not maintaining confidentiality could be disastrous for the health and wellbeing of the affected individuals. These consequences may include HIV-related stigma, isolation, and loss of a job. It was reported that disclosure to close families and friends is a necessity for a better adherence to treatment, adopting safer sex options among sexual partners or promoting HIV testing within close family members. Concealing of HIV positive status helps some participants to retain their privacy. Although health professionals need to engage more with patients infected with HIV on the importance of disclosure among partners, non-disclosure may also be beneficial in situations where there is a risk of domestic violence as reported in the systematic review for this study. Non-disclosure of HIV in the workplace may be beneficial in situations where there is a likelihood that it would result in stigma, discrimination, and loss of a job.

Non-disclosure of HIV status has psychosocial implications. Being diagnosed with HIV can be distressing, and that may lead to chronic stress and depression when infected individuals are less able to seek help as a result of the fear of stigma. Non-disclosure of status may also affect accessing workplace adjustment as reported earlier in this chapter. To have access to workplace adjustments such as modification of work schedule, permission to meet doctor's appointments, flexible work patterns, and shortening work days, there must be convincing

reasons to an employer of why adjustments are needed. Although few of the participants disclosed their status at work, the majority of the participants in this study made excuses to access workplace adjustment. These include family responsibility (e.g. picking a child up from school) or general health check-up without being specific. However, making excuses may not stop PLWHA from feeling stressed because of the burden of keeping the secret of their health status. They may also continue to find it difficult to express themselves freely in the workplace without the fear that someone may find out about their HIV-positive status. These findings indicated that the majority of the participants had the choice to disclose or not in the workplace and each act has consequences.

Nevertheless, this study found that not everyone has the choice of a voluntary disclosure. For example, some participants disclosed because of a workplace requirement. Disclosure on the basis of a workplace requirement leaves an infected person worried about confidentiality in the workplace and gives the concern that disclosure of their personal information was not under their personal control.

Ajzen (2011) emphasized the importance of having control over an action: the stronger they perceived control over their behaviour, the stronger their intentions to carry out such action. Not having control over a situation may increase the pressure to perform an action. For instance, participants who run out of excuses for regular absence at work may not have control over their decision to disclose their HIV positive status or not in their workplace if their employers asked for reasons for their inconsistency at work. Losing control over such a decision may result in an involuntary disclosure of their HIV positive status in the workplace. The findings show that when PLWHA have not disclosed and were no longer able to provide excuses for continuous absence from work, they may consider disclosing their HIV positive status to their employer for a work adjustment. Interestingly, participants perceived that their work pattern has an influence on whether they disclosed their status or not. In this study, an employee who does flexible shift work preferred to conceal their status because they were able to plan their work alongside their regular doctor's visits. However, working within the

common working hours, for example, 8 am-4pm or 9 am-5 pm, may not be flexible enough to accommodate visiting a doctor. Hence, a flexible working hour or shift pattern is necessary for employees living with HIV/AIDS to accommodate their regular hospital visits to health services, otherwise, PLWHA will continue to miss their hospital appointment and that could lead to further health complications. Some participants increase their work performance to create the perception of being seen as a 'valued' employee so that there will not be any suspicion of their condition. The consequences may lead to employees missing their doctor's visits because they want to make the impression that they are 'hard working' and so they increase their work productivity to enhance this positive impression. Therefore, HIV disclosure in the workplace becomes necessary in accessing workplace adjustment. In requesting workplace adjustment, the decision to disclose or not in the workplace needs to be made.

Meanwhile, PLWHA disclosed within their professional networks as a duty of care to those who were newly diagnosed with HIV. It was reported that PLWHA may disclose to a work colleague, not necessarily to seek work adjustment, but to assist a colleague who is newly infected with HIV to adhere to treatment. In this type of disclosure to someone with similar conditions, there is less worry about unconsented disclosure. This is because participants perceived that information about their status is safe with colleagues living with a similar condition as they continue to care for each other.

PLWHA reported reactions received from their close family members and in the workplace after disclosing their HIV positive status. Within their close networks, supportive reactions were most reported. It was found that after disclosure to a close family member, especially to a partner, emotional and financial support was received. However, disclosure to family members does not always come with positive outcomes. It was reported that PLWHA faced negative reactions from their family members, including stigma, divorce, domestic violence, and blame. Meanwhile, negative reactions were mostly reported by PLWHA in their workplace. These include disadvantaged career progress, loss of employment, and difficulty in adhering to treatment. However, some participants reported that disclosure of their HIV positive status had

made it possible to have a flexible working pattern. It is therefore evident in this research that PLWHA used a pragmatic approach when taking a decision to disclose or not, both with their close family members and in the workplace. That is, different individuals perceived disclosure in different ways depending on their circumstances.

This study highlighted that when there is no assurance of beneficial outcomes of disclosure, there are chances that PLWHA would conceal their HIV positive status. The findings presented could be of interest to health professionals in charge of HIV patients to know how best to support PLWHA, especially employed people who may be struggling to attend their appointment because of their decision to conceal their status. The support can be in terms of providing flexible days to access treatment. It was found that PLWHA could only access healthcare on weekdays: this could be challenging for employees who struggle to access regular healthcare. Provision of access to healthcare at weekends may reduce regular absence from work as a result of taking time off work to attend appointments. Although the Labour Congress of Nigeria made provisions for every employee, including people infected or affected by HIV, to work without fear of discrimination (Federal Ministry of Labour and Productivity, (FMLP) 2013), this study reported PLWHA were subjected to discrimination and loss of job as a result of disclosure of their status in the workplace.

Since more than half of the participants did not disclose their status in the workplace due to their invisible symptoms but developed their coping strategies such as making excuses for being absent from work, or disclosure of other less stigmatised conditions to attend doctor's appointments and access treatment, this study reveals if disclosure in the workplace is needed to gain support as some participants were able to cope with their work responsibilities and access treatment without disclosing their HIV positive status. Meanwhile, it is important to note that non-disclosure was found to be distressing in this study as PLWHA may continue to live in constant fear or suspicion as a result of concealing their status.

6.1 Implications for policy and practice

The outcomes of this research have implications for policy, organisations, and practice as will be briefly explained below.

6.1.1 Implications for policymakers

HIV disclosure in the workplace has the potential to help policymakers in providing employees living with HIV/AIDS more protection against any form of discrimination or stigma in the workplace. This study reported that PLWHA were afraid of losing their jobs if they disclosed their status in the workplace and some actually reported loss of employment or change of career as a result of disclosure. Policymakers can promote access to social services for PLWHA in case they lose their job as a result of ill health. This can be done by gaining the support of the federal government to create welfare services for PLWHA who have little or no source of income.

The Nigerian government launched a national workplace policy on HIV/AIDS in 2005 (FMLP, 2013). This policy is based on the principles of social justice, equity and human rights for employees living with HIV/AIDS. Its targeted workplaces to ensure the workplace is a safe environment where HIV-related stigma and discrimination do not thrive. It also addresses the impact of the burden of stigma and discrimination against workers infected or affected by HIV and AIDS. However, few organisations who responded were organisations that focused on HIV/AIDS programming. More needs to be done to be inclusive of all organisations and stakeholders.

Confidentiality should be promoted by all organisations. This study affirms that more campaigns are needed to target workplaces against breach of confidentiality of their employees who disclose at work. In organisations where HIV testing is required before a successful job application, data protection policies must be made clear to all employees. This may promote trust and transparency between the management and employees in an organisation.

6.1.2 Implications for organisations

This study reported a consistent absence from work of PLWHA and this may have some financial implications for an organisation. The financial implications may be a direct or indirect cost to an organisation such as recruiting and training replacement workers, low productivity or insurance cost. The organisation can do more in providing access to counselling and support in the workplace for PLWHA who may want to discuss their overall wellbeing with a healthcare professional in the workplace without the need to take time off work. Organisations may also recognise the need to set aside direct financial assistance for their employees who have disclosed in the workplace.

The organisation should recognise the implication of regular checks to the wellbeing of an employee who is infected with HIV/AIDS. This study reported work adjustment or flexible shifts as a way to help PLWHA to attend their regular medical checks. The inability to attend regular medical checks may have an impact on their overall health status and consequently lead to a lack of trained employees in an organisation.

In organisations where the HIV status of every employee must be known as a result of the nature of the job, organising HIV testing off-site of an enterprise minimises suspicion by fellow workers and promotes privacy of an employee in the workplace.

6.1.3 Implications for practice

This study shows that HIV disclosure is not recommended in all circumstances in the workplace where the risk of disclosure outweighs its benefit. From a practical perspective, non-disclosure should also be part of the options that could be adopted and encouraged in cases where disclosure could affect the rights of PLWHA in the workplace. Counselling/support team and healthcare professionals may be involved in providing advice to employed PLWHA on how to deal with disclosure at work.

This study reported that PLWHA could only access health services on weekdays. The healthcare system may promote flexible access to facilities in order for employed PLWHA to

conveniently pick up their medications. Involuntary disclosure may be limited when PLWHA have flexible work and can go for their medical checks without the need to request time off work from their employers. Easy accessibility also includes patients' medications being delivered to their homes via a home-based service. However, the delivery of medication to a patient's home could lead to stigma for themselves and their family members (Tam *et al*. 2011). Provision of various options to access treatment could have positive implications for the overall management of their condition.

One of the ways to provide emotional support for PLWHA is to connect them with other people who have the same or similar health conditions. This can be in form of patients' groups led by patients. In this study, some participants acknowledged the importance of this platform to support one another in managing their condition. This study reported that PLWHA who attend some form of support group meetings are able to share their experiences and form a close relationship with others. This also provided them with the opportunity to encourage one another and to share their worries and strategies on dealing with disclosure in the workplace with one another. However, the support group meetings have only been successfully organised within the hospital settings but not in the workplace. This also shows that PLWHA were careful of identifying themselves with their conditions in the workplace because of the fear of stigma and discrimination. Although more support groups should be encouraged by healthcare professionals so that support platforms will be available for PLWHA to connect with others living with the same or similar conditions, more importantly, workplace policies should be promoted that allow PLWHA to freely talk about their condition with other colleagues in the workplace without the fear of stigma.

6.2 Strengths and weaknesses/limitations

This section explains the main strengths and weaknesses/limitations of this study

6.2.1 Research approach

The use of two approaches (the systematic review and the qualitative study) in this thesis was a strength. It allowed for an in-depth investigation of HIV disclosure among people living with HIV/AIDS in Nigeria with their intimate relationships, family members and within their social and professional networks.

The findings of the systematic review were able to provide information on the most common form of disclosure - disclosure towards sexual partners. To the best of the authors' knowledge, this systematic review[8] of HIV disclosure is the first to be published among PLWHA in Nigeria.

The primary study focuses on employed people living with HIV/AIDS who were accessing treatment from a hospital. The data contain information relevant to HIV disclosure among people living with HIV in the workplace. This contributes to the strength of the study. In addition, qualitative research may guarantee confidentiality as all identifiable information was deleted during data analysis, and participants' words and quotes were used without revealing personal information of the participants.

6.2.2 Settings

Collection of data in Nigeria among people living with HIV/AIDS was a strength of this study. The researcher gathered the data by travelling to Nigeria to conduct the interviews. The use of other means such as recruiting a research assistant may not be efficient for this study. Also, limited time and resources such as staff payment and training may mean it is too expensive and time-consuming.

The findings of the qualitative study indicate that employers might terminate the employment of an infected employee as a result of disclosure. This study might be more comprehensive if information about employers' perspectives was explored as such information would be used to understand how HIV disclosure is handled in the workplace.

[8] See the abstract of the published article in Appendix 11.

6.2.3 Sample

In the systematic review, only articles published in English were included. This may not have a significant effect on the findings as the official language of the country is English (Aito, 2002), and academic journals are largely expected to be published in English. Finally, the systematic review findings only reported studies where full-text could be retrieved. Others, however, may have been excluded creating a risk of missing out some current evidence, or articles that were not available on 'open' peer-review journals (Boland, Cherry & Dickson, 2014).

Although this study may not represent the total number of employed people living with HIV in Nigeria, it was conducted in a hospital where HIV-related facilities were made accessible to HIV patients. It is also important to note that access to HIV patients in Nigeria is very challenging due to the stigma associated with this condition. However, this was a strength of this study as a researcher was able to conduct face-to-face interviews with these patients.

Including other settings in the study may have provided different perspectives, for example, including HIV patients from both the government and the private hospitals may have provided some similarities and differences in their disclosure experience in the workplace. Lack of access to patients in government hospitals and limited resources prevented the researcher from including these two hospitals.

Similarly, recruiting participants based on different skills categories, such as the unskilled, semi-skilled, skilled and professionals, may have provided more insight into how that could play out in their HIV disclosure and adherence to treatment in their various workplaces. However, the researcher was open to recruiting any potential participants who met the study's eligibility criteria: this improves the number of participants recruited in this study.

6.3 Suggestions for future research

As some participants struggled to take time off work to attend doctor's appointments, future research could explore difficulty in attending a doctor's appointment and the overall management of HIV. Research may also explore other strategies used by PLWHA to conceal

their status in the workplace and how the decision not to disclose their HIV positive status played out in their adherence to treatment.

As systematic review findings did not show sufficient information on HIV disclosure in the workplace among PLWHA, there is scope to collect and synthesise research-based evidence on HIV disclosure in the workplace among PLWHA from other countries. This would allow the findings of this study to be validated and be representative of a larger population.

The qualitative study found that HIV disclosure in the workplace results in loss of job or disadvantage to career progression. Future research will explore employers' perspectives on the way disclosure is being handled in their organisations. Also, work adjustments available for an individual who may disclose a chronic illness such as HIV/AIDS in the workplace can be considered. Future research may include a longitudinal study to understand how the perceptions of people who have not disclosed their HIV positive status change over time.

Information gathered from this proposed research would be useful for policymakers and researchers alike. Future research may also involve the perspective of people that have experienced loss of job or change of job as a result of disclosure in their workplaces. The information could help to understand their coping mechanism during this time and how they were able to meet their financial challenges as a result of unemployment.

6.3.1 Dissemination of the study findings

It is important that this study findings are disseminated to the public to enrich the pool of the existing literature on HIV disclosure in the workplace in Nigeria and worldwide. Also, disseminating the study findings will strengthen and contribute to the argument on the perception of people living with HIV/AIDS in disclosing their HIV status, and contribute to the formulation of effective healthcare policies. Hence, some aspects of this thesis were published, and others are in the process of publication. These findings include the concept of trust, support or confidentiality and how these influenced HIV-related stigma or the fear of stigma in the workplace, the impact of flexible working conditions in the management of

HIV/AIDS by employees living with HIV/AIDS, the implications of non-disclosure, and the influence of support groups in the management of HIV. Articles that have been accepted for publications include the systematic review findings and some aspects of the qualitative research findings. However, it is expected that some other aspects of the qualitative findings will be submitted to a reputable journal for publication such as African Health Journal, Health Education and Behaviour, and BMC Public Health. Details of the published and under review articles are found in 'peer-reviewed publication' section, page –xvi of this thesis.

6.4 Personal reflection on my learning journey

Reflection can be adopted through an interrogative approach of thinking and learning through a doctoral process such as forming topic, developing a research protocol, data collection, analysing and writing up. Husebo, O'Regan & Nestle (2015) referred to reflection as a process of learning from an experience by considering previous knowledge and incorporating new knowledge into future research.

This reflective section will use Gibbs' (1988) model to reflect on my experience as a doctoral student. Gibbs (1988) stated that although it is important to have an experience in order to learn, it is also vital to reflect on such experience before it is forgotten. The feelings and thoughts generated from this experience will form a new concept that would tackle a new future challenge.

Figure 15: Gibbs (1988) reflective model

Throughout this journey, there were so many learning events which are hard to explore in such a short section. However, in this reflection section, I will outline my experience using Gibbs' reflective cycle checklists (1988) to explain my situation, how I felt, what I did, and the lesson learned, and my action plan.

6.4.1 Description, feelings, and evaluation

Time management

When I started my doctoral programme, having to manage my personal and professional life was very hard to achieve and to some extent, frustrating. Therefore, to overcome my anxiety, I listed those things I enjoyed doing that take most of my time such as spending time with friends on social media, discussing politics and watching movies. The time was running quickly, and my academic progress was in danger, I understood that I had to do something about it to have enough time for my PhD. In planning my weekly task, I ensured I planned an achievable and relevant task. I built a list of tasks from each of my supervisory meetings to meet the university regulations. Using this to plan my weekly tasks contributed to my success at every stage of my research. With good planning, I developed a good habit in the earliest stage of my research. However, unexpected circumstances challenged my planning which explained the influence of my personal life and responsibilities that revolved around my PhD.

Things became much more challenging and that meant I had to give extra time to meet my academic and personal responsibilities.

Managing personal, social and professional networks

I had it in my head that other things would automatically deal with themselves while my programme progressed, so I failed to plan for eventualities. Other aspects of my life would show some demands: marriage, pregnancy, having a child, commitment to my faith, coping with finances and giving time for friends. This is one of the difficult adjustments I had to make. My fear was not being there for all of the aspects that life demands. At one stage, I had to choose to go to the library on Sunday or study through the night to work on my research while missing church service, missing the opportunity to meet with friends in church and playing musical instruments which, I do every Sunday. I also learned to tell friends to notify me before coming to visit so that their visit would not disrupt my plan for the day. I could remember one of my friends saying, 'Have you now turned to *oyinbo* people [westerners] that we have to tell you before visiting you?' In a Nigerian culture, people enjoy giving friends and family members surprise visits which is an acceptable fun way in a Nigerian culture. However, I learned to say no to this habit so that I could always complete my everyday activities. I also had to choose which workshop/training organised by the university was relevant to my research instead of attending all the workshops. For instance, I knew from the early stage of my PhD that my research methodology would be a qualitative approach. Therefore, in my second year, I chose workshops/training relevant to my research so that my time could be fully dedicated to what was needed.

In the midst of all these challenges, I got pregnant. I was writing up my thesis when I knew of my pregnancy. It took me months before I accepted my pregnancy as I saw it as another distraction from my studies. I could not inform my supervisory team early because I thought they do not have to know about my personal life. I also thought of working harder to submit

my thesis before my pregnancy starts to be visible because I saw my pregnancy as an interruption to my study. It was until I admitted this as one important aspect of my life and I was able to plan my work to go hand-in-hand with my programme. I was then able to develop a better way to plan my study together with events happening in my life so that one did not affect the other. It took me time to recognise the importance of asking for and accepting help. These included communicating with my supervisors, understanding the university policies on pregnancy and maternity leave and accessing medical support related to my pregnancy.

Family support

I was very fortunate to come from a family where education is a priority. Although both my parents did not have a university degree, they were determined that all of their children would attain a post-graduate qualification to improve their children's opportunities to succeed in life. However, the doctoral programme was a journey without a family 'role model', as I am the first in my family to reach this level of education. One thing I cannot dispute is the fact that I have a family support that kept me sane and reminded me of why I am doing this when it seemed I had forgotten and was almost giving up. My support networks also included my husband who stood by me to encourage me, the church I attend; and my love for music is sometimes a medicine against stress.

Developing independent skills

Even with the combination of the aforementioned support networks, PhD seems to be a lonely process. Spending all nights writing drafts, reading and attending to supervisors' feedback needed a quiet time but could turn into a lonely time. The bulk of the work is expected to be done independently. The lonely period started at the early stage of the research when trying to form clear research aims and objectives, reviewing the literature and determining the methodology that best answers the research question. In addition, there is a feeling of self-doubt or the thought of quitting. The feelings of trying to explain my research to someone and

their reacting of nodding their heads and giving that smile that is not genuine could also increase the feeling of self-doubt; doubting if I am actually doing the right thing and if what I am doing is worth it. These were the feelings that made the journey lonely. One of the ways I overcame my self-doubt was to identify fellow students who were a year or two ahead of me and communicate with them whenever I needed the advice of how to get things done and how to access certain materials for my research. Through communicating with these fellow students, I learned from their good and bad experiences, and that sharpened my planning and how to do things differently to get a better result.

I also attended PhD presentations where I met with other PhD students to discuss our research. I presented my work during those meetings where fellow students asked me questions and I was able to develop the confidence in myself and my research. I integrated the feedback from fellow students and academics but sometimes I found it very hard to digest. As I progressed, I became a mentor for new students. This gave me more confidence and erased self-doubt.

Developing work-life balance

During my PhD journey, I rewarded myself for a job done, and sometimes I did that to 'treat' myself in what I call fruitful procrastination. It is a common perception that a doctoral student only eats, sleeps and studies, but I found out it is also okay to give time for self-care. This has taught me to constantly remember that I have a life outside of my research programme. Some of that fun time I enjoyed as self-care was going out with my family on weekends to visit new close-by places we had not been to. During this trip, I had the satisfaction that I was rewarded because I was able to achieve my goal. However, in a situation where my goal was not achieved due to delay due to my procrastination, I deprived myself of having the planned fun I should have had. As personal responsibilities were confronting my research, it became extremely difficult to create time to care for myself and sometimes I got a less than ideal number of hours to sleep at night.

I made sure I did not miss any of my appointments during my pregnancy. I consistently communicated with my midwife if I needed some clarifications of any signs I noticed. During this time, I registered for a “5-week first-time parenting” course so that I could create time to care for myself. I paid attention to my sitting position and my meals, and I also planned a break in between studying for the benefit of myself and the baby. Apart from the self-care, I also sought support that would help me to care for myself and my baby. I understood sharing this information with my supervisors and the university might bring about support tailored to my needs and condition. Despite being aware of the support I might receive if I disclosed my pregnancy, worries about being perceived as ‘weak’ and treated differently delayed my decision to inform my supervisors. I came to the realisation that I am a human being and being open about my needs could ease what comes with a doctoral research. We organised both face and Skype supervisory meetings to avoid the stress of travel.

6.4.2 Action plan

Developing a good habit is a good thing. However, rewarding myself with what I referred to as a ‘bad habit’ has helped me to get engaged with other things to relax my brain. I tried to incorporate having a walk in the park or studying in a quiet park, but I was not able to work this out effectively. I had a busy park close to my house and this was not useful for quiet meditation. However, if I had to consider doing things differently that would make me break away from studying for a particular period, I would choose to go to a gym. Staying in a quiet place was also useful for me during my data analysis. This was when I needed a full concentration to understand how each participant made sense of their experience of disclosure in the workplace. If I had been able to select and use quiet places more frequently, it could have influenced the speed to finish up my interview transcription and data analysis rather than spending over 4 months in transcribing and analysing the interview transcripts.

Managing my academic life to accommodate personal and social life could strengthen the psychological state of the student. It is important that time is given to friends and families.

However, they need to understand the project at hand and what is required to be successful. When this is done, close relatives would be a strong support network.

My dilemma of disclosure of my pregnancy has strongly reminded me of the difficulties PLWHA face and have to consider before disclosing their status to someone who they think could understand their challenges and offer support. Although I identified family members as an important support network which was beneficial, I did not, at any point, access a professional support such as the student engagement team. Perhaps I do not have a sufficient understanding of the support I might get from them. I knew about some of the university support networks when I was pregnant, and I had to give a formal notice of my pregnancy.

Of course, I am fully aware that the experience of pregnancy as a condition cannot be compared to living with HIV/AIDS. However, both events have some similarities. One of these is the struggle to disclose my pregnancy to my supervisors and this is related to the findings of this study where PLWHA struggled to disclose their status in the workplace. However, disclosure to access support helped the HIV infected individuals to cope with their condition. In addition, having a good quality relationship within a professional network is associated with trust, respect and the ability to share information, resources, and perspectives (Phillips, Rothbard and Dumas, 2009). However, it is not guaranteed that sharing personal information would yield a positive relationship within a professional network such as in the workplace or in the institution. Hence, the decision to share personal information must be well thought-through especially when dealing with sensitive information.

I received support from my family members, faith group, supervisors, the university and my community. All these support networks contributed immensely to my psychological social mental and academic progress. In the future, I would plan to get enough information about professional services to help me through. This is needed because a PhD can sometimes be lonely even when in the midst of friends and families. The feeling occurred when I assumed the challenges in my research cannot be understood by friends, even at the early stage, which

affected my confidence. It took me a while to realise that it's okay to feel that way at the early stage of the research, but as I progressed, I began to have a conversation confidently about my research with people with or without research knowledge. My self-care was not good enough. I had lost what I enjoyed doing and replaced them with whatever activities that were related to studying such as reading books and seeing scientific movies. Having a child to look after has redirected my interest in other activities that would benefit my child. This includes attending a children's centre once a week to sing and recite children's rhythms. However, attending this activity was also used to break myself away from my research work and to do things entirely different from what I use most of my time for.

My experience in doing this PhD changed my life beyond recognition. It made me become an entirely different person from what I was at the start of my PhD. This includes redefining my relationship with people, modifying my social network and behaviour, being more effective in managing responsibilities and redefining my priorities. It was indeed a journey that, within four years, I have become a wife, a mother and hopefully a successful researcher/academic.

References

Adebayo, A.M., Ilesanmi, O.S., Omotoso, B.A., Ayodeji, O.O., Kareem, A.O. & Alele, F.O. (2014) 'Disclosure to sexual partner and condom use among HIV positive clients attending ART clinic at a tertiary health facility in South West Nigeria', *Pan African Medical Journal,* 18 pp.245-245.

Adebiyi, I. & Ajuwon, A.J. (2015) 'Sexual behaviour and serostatus disclosure among persons living with HIV in Ibadan, Nigeria', *African Journal of Biomedical Research,* 18 (1), pp.69-80.

Adekanle, D.A., Olowookere, S.A., Adewole, A.D., Adeleke, N.A., Abioye-Kuteyi, E.A. & Ijadunola, M.Y. (2015) 'Sexual experiences of married HIV positive women in Osogbo, southwest Nigeria: role of inappropriate status disclosure', *BMC Women's Health,* 15 (1), pp.1-11.

Adeoye-Agboola, D., Evans, H., Hewson, D. & Pappas, Y. (2016) 'Review Paper: Factors influencing HIV disclosure among people living with HIV/AIDS in Nigeria: a systematic review using narrative synthesis and meta-analysis', *Public Health,* 136 pp.13-28.

Afolayan, J.A., Wakeel, A.T. & Donald, B. (2014) 'Psychosocial determinants of self-disclosure of HIV positive status', *Archives of Applied Science Research,* 6 (1), pp.184-191.

Aggleton, P. & Homans, H. (1988) Social aspects of AIDS. London: The Falmer Press.

Aguwa, E.N., Arinze-Onyia, S., Okwaraji, F. & Modebe, I. (2015) 'Assessment of Workplace Stigma and Discrimination among People Living with HIV/AIDS Attending Antiretroviral Clinics in Health Institutions in Enugu, Southeast Nigeria', *The West Indian Medical Journal,* 65 (1), pp.98-105.

Aidala, A.A., Wilson, M.G., Shubert, V., Gogolishvili, D., Globerman, J., Rueda, S., Bozack, A.K., Caban, M. & Rourke, S.B. (2016) 'Housing Status, Medical Care, and Health Outcomes Among People Living With HIV/AIDS: A Systematic Review', *American Journal of Public Health,* 106 (1), pp.1-23.

Aito, E. (2002) 'National and Official Languages in Nigeria: Reflections on Linguistic Interference and the Impact of Language Policy and Politics on Minority Languages.', *Proceedings of the 4th International Symposium on Bilingualism,* pp.18-38.

Ajzen, I. (2011) 'The theory of planned behaviour: Reactions and reflections', *Psychology & Health,* 26 (9), pp.1113-1127.

Ali, S. & Kelly, M. (2012) 'Ethics and social research', in Seale, C. (ed.) *Researching society and culture*. Sage Publication: London, pp. 58-76.

American Psychological Association (APA) (2015) HIV/AIDS & Socioeconomic status [Online] Available at: http://www.apa.org/pi/ses/resources/publications/factsheet-hiv-aids.pdf (Accessed: 03 November, 2015)

Amo-Adjei, J. & Darteh, E.K.M. (2013) 'Drivers of young people's attitudes towards HIV/AIDS stigma and discrimination: evidence from Ghana', *African Journal of Reproductive Health,* 17 (4), pp.51-59.

Amole, I.O., Durodola, A.O., Adeniran, A., Awotunde, O.T. & Adesina, S.A. (2015) 'Prevalence of pain in family medicine clinic of Bowen University Teaching Hospital, Ogbomoso, Nigeria', *British Journal of Medicine and Medical Research,* 9 (1), pp.1-6.

Amole, O.I., OlaOlorun, D.A. & Odeigah, O.L. (2013) 'Body size and abnormal lipids among adult patients at the Baptist Medical centre, Ogbomoso, Nigeria', *African Health Sciences,* 13 (1), pp.32-37.

Amoran, O.E. (2012) 'Predictors of disclosure of sero-status to sexual partners among people living with HIV/AIDS in ogun state, nigeria', *Nigerian Journal of Clinical Practice,* 15 (4), pp.385-390.

Anciaes, P.R. (2017) Social determinants of health. London: *Salem Press.*

Annequin, M., Lert, F., Spire, B. & Dray-Spira, R. (2015) 'Has the employment status of people living with HIV changed since the early 2000s?', *AIDS,* 29 (12), pp.1537-1547.

Annequin, M., Lert, F., Spire, B., Dray-Spira, R. & Null, N. (2016) 'Increase in Unemployment over the 2000's: Comparison between People Living with HIV and the French General Population', *Plos One,* 11 (11), pp.1-17.

Arimoto, Y., Ito, S., Kudo, Y. & Tsukada, K. (2013) 'Stigma, social relationship and HIV testing in the workplace: evidence from South Africa', *IDE Discussion Papers,* pp.1-35.

Arinze-Onyia, S.U., Modebe, I. & Aguwa, E.N. (2016) 'Disclosure of Hiv Status by Persons Living with Hiv/aids in their Workplaces and Post Disclosure Consequences on the Patients', *Journal of Experimental Research, Vol 3 (2016),* 3 (1), pp.32-40.

Arnold, J. (2010) *Work psychology: understanding human behaviour in the workplace* 5th edn Harlow: Pearson Education.

Averting HIV and AIDS (AHA) (2016) HIV AND AIDS in Nigeria [Online] Available at: https://www.avert.org/professionals/hiv-around-world/sub-saharan-africa/overview (Accessed: 28 November, 2017)

Awaworyi Churchill, S. & Mishra, V. (2017) 'Trust, social networks and subjective wellbeing in China', *Social Indicators Research,* 132 (1), pp.313-339.

Awofala, A.A. & Ogundele, O.E. (2016) 'Review: HIV epidemiology in Nigeria', *Saudi Journal of Biological Sciences,* Available at: http://www.sciencedirect.com/science/article/pii/S1319562X16300110 (Accessed: 21 March, 2017).

Ayodele, O. (2017) 'The Theory of Planned Behavior as a Predictor of HIV Testing Intention', *American Journal of Health Behavior,* 41 (2), pp.147-151.

Babcock, J.H. (1998) 'Involving family and significant others in acute care. In: Aronstein DM, Thompson B.J, editors. HIV and social work. Harrington; Binghamton, NY: 1998. pp. 101–108.

Baltes, P. B., and Baltes, M. M. ''Psychological Perspectives on Successful Aging: The Model of Selective Optimization with Compensation.'' In *Successful Aging: Perspectives from the Behavioral Sciences.* Edited by P. B. Baltes and M. M. Baltes. Cambridge, U.K.: Cambridge University Press, 1990, pp. 1–34.

Barnett, Tony & Blaikie, P. (1992) *AIDS in Africa: its present and future impact*. London: Belhaven Press.

Bartley, M., Ferrie, J. & Montgomery, S. M. (2000) 'Living in high-unemployment economy: understanding the health consequences', in Marmot, M. & Wilkinson, R.G. (ed.) *Social determinants of health* Oxford: Oxford University Press, pp. 81-97.

Bartley, M., Ferrie, J. & Montgomery, S. M. (2006) 'Health and labour market disadvantage: unemployment, non-employment, and job insecurity', in Marmot, M. & Wilkinson, R.G. (ed.) *Social determinants of health* Oxford: Oxford University Press, pp. 79-92.

Bashir, S. (2011) 'HIV / AIDS stigma at the workplace: exploratory findings from Pakistan: original article', *Sahara,* 8 (3), pp.156-161.

Bashorun, A., Nguku, P., Kawu, I., Ngige, E., Ogundiran, A., Sabitu, K., Nasidi, A. & Nsubuga, P. (2014) 'A description of HIV prevalence trends in Nigeria from 2001 to 2010: what is the progress, where is the problem?', *The Pan African Medical Journal,* 18 (1), pp.3.

Bateganya, M.H., Amanyeiwe, U., Roxo, U. & Dong, M. (2015) 'Impact of support groups for people living with HIV on clinical outcomes: A systematic review of the literature', *JAIDS Journal of Acquired Immune Deficiency Syndromes,* 68 pp.368-374.

Beauchamp, T., Childress, J. (2009) *Principles of biomedical ethics.* 6thedn. New York: Oxford University Press.

Bergin, M. (2011) 'Nvivo 8 and consistency in data analysis: Reflecting on the use of a qualitative data analysis program', *Nurse Researcher,* 18 (3), pp.6-12.

Bernard, E.J. (2015) Nigeria: Senate Passes Law Criminalising Hiv Non-Disclosure, Exposure And Transmission With Vague And Overly Broad Statutes In The Sexual Offences Bill [Online] Available at: http://www.hivjustice.net/news/nigeria-senate-passes-law-criminalising-hiv-non-disclosure-exposure-and-transmission-with-vague-and-overly-broad-statutes-in-the-sexual-offences-bill/ (Accessed: 4 December 2017)

Bettany-Saltikov (2012) *How to do a Systematic Literature Review in Nursing*. New York: Open University Press

Bhatt, C. (2012) 'Doing a dissertation', in Seale, C. (ed.) *Researching society and culture*. Sage Publication: London, pp. 154-178

Birenbaum, A. (1970) 'On Managing a Courtesy Stigma', *Journal of Health and Social Behavior,* 11 (3), pp.196-206.

Bloch, A. (2012) 'Statistical reasoning: from one to two variables', in Seale, C. (ed.) *Researching society and culture*. Sage Publication: London, pp.328-348.

Bogart, L.M., Skinner, D., Weinhardt, L.S., Glasman, L., Sitzler, C., Toefy, Y. & Kalichman, S.C. (2011) 'HIV/AIDS misconceptions may be associated with condom use among black South Africans: an exploratory analysis', *African Journal of AIDS Research,* 10 (2), pp.181-187.

Boland, A. Cherry, M. G & Dickson, R. (2014) Doing a systematic review: a student's guide. Los Angeles, California: SAGE.

Bond, V.A. (2010) 'It is not an easy decision on HIV, especially in Zambia': opting for silence, limited disclosure and implicit understanding to retain a wider identity', *AIDS Care,* 22 (no issue), pp.6-13.

Boone, M.R., Cherenack, E.M. & Wilson, P.A. (2015) 'Self-Efficacy for Sexual Risk Reduction and Partner HIV Status as Correlates of Sexual Risk Behavior Among HIV-Positive Adolescent Girls and Women', *AIDS Patient Care and STDs,* 29 (6), pp.346-353.

Boslaugh, S.E. (2013) 'Theory of planned behaviour', *Salem Press Encyclopaedias* [Online] Available at: http://0-eds.b.ebscohost.com.brum.beds.ac.uk/eds/detail/detail?vid=2&sid=0b47b244-5686-4747-8470-f00995af48ba%40sessionmgr103&bdata=JnNpdGU9ZWRzLWxpdmUmc2NvcGU9c2l0ZQ%3d%3d#AN=89677651&db=ers (Accessed: 6 September, 2017).

Bowling, A. (2009) *Research methods in health: investigating health and health services*. 3rd (edn) Maiden: Open University Press

Braun, V. & Clarke V. (2013) *Successful qualitative research: a practical guide for beginners*. London: SAGE

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3 (2). pp. 77-101.

Brennan, K.A.M. & Creaven, A. (2016) 'Living with invisible illness: social support experiences of individuals with systemic lupus erythematosus', *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation,* 25 (5), pp.1227-1235.

Breuer, N.L. (2005) 'Teaching the HIV-positive client how to manage the workplace', *Journal of Vocational Rehabilitation,* 22 (3), pp.163-169.

Breen, L., J. (2007) 'The researcher `in the middle?: Negotiating the insider/outsider dichotomy', *The Australian Community Psychologist,* 19 (1), pp.163-174.

Briesacher, A.B. (2014) Integrating Stereotype Threat into Identity Theory and Social Identity Theory. Kent State University.

Brocki, J.M. & Wearden, A.J. (2006) 'A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology', *Psychology & Health,* 21 (1), pp.87-108.

Brohan, E., Henderson, C., Wheat, K., Malcolm, E., Clement, S., Barley, E.A., Slade, M. & Thornicroft, G. (2012) 'Systematic review of beliefs, behaviours and influencing factors associated with disclosure of a mental health problem in the workplace', *BMC Psychiatry,* 12 pp.11-11.

Brown, B., J., Oladokun, R., E., Osinusi, K., Ochigbo, S., Adewole, I., F. & Kanki, P. (2011) 'Disclosure of HIV status to infected children in a nigerian HIV care programme', *AIDS Care,* 23 (9), pp.1053-1058

Brown, M.J., Serovich, J.M., Kimberly, J.A. & Umasabor-Bubu, O. (2015) 'Disclosure and Self-Efficacy Among HIV-Positive Men Who Have Sex with Men: A Comparison Between Older and Younger Adults', *AIDS Patient Care and STDs,* 29 (11), pp.625-633.

Bryman, A. (2012) *Social research methods*. 4th edn Oxford: Oxford University Press

Buck, R., Porteous, C., Wynne-Jones, G., Marsh, K., Phillips, C. & Main, C. (2011) 'Challenges to Remaining at Work with Common Health Problems: What Helps and What Influence Do Organisational Policies Have?', *Journal of Occupational Rehabilitation,* 21 (4), pp.501-512.

Burton, J. (2010) WHO Healthy Workplace Framework and Model. World Health Organisation: Geneva.

Byrne, B. (2012) 'Qualitative interviewing', in Seale, C. (ed.) Researching society and culture. Sage Publication: London, pp. 206-266.

Caldwell, K., Henshaw, L., Taylon, G. (2010) 'Developing a framework for critiquing health research: an early evaluation', *Nurse Education Today*, [Online] Available at: https://www.researchgate.net/publication/49708693_Developing_a_framework_for_critiquing_health_research_an_early_evaluation (Accessed: 30th March, 2015).

Cama, E., Brener, L., Slavin, S. & de Wit, J. (2015) 'The impact of HIV treatment-related stigma on uptake of antiretroviral therapy', *AIDS Care,* 27 (6), pp.739-742.

Centre for Reviews and Dissemination (2009) 'Systematic Review' [Online] Available at: http://www.york.ac.uk/inst/crd/pdf/Systematic_Reviews.pdf (Accessed: 30th October, 2014).

Centres for Disease Control and Prevention (2015) Opportunistic infections [Online] Available at: http://www.cdc.gov/hiv/basics/livingwithhiv/opportunisticinfections.html (Accessed: 31 May, 2015).

Chandran, V., Madi, D., Chowta, N., Ramapuram, J., Achappa, B., Jose, H. & Bhaskaran, U. (2016) 'Caregiver burden among adults caring for people living with HIV/AIDS (PLWHA) in Southern India', *Journal of Clinical and Diagnostic Research,* 10 (5), pp.41-43.

Charlton, M., Lapthorn, N. & Moncrieff. (2014) 'A questioning approach to fieldwork', *Teaching Geography,* pp.71-73.

Chaudoir, S.R. & Fisher, J.D. (2010) 'The disclosure processes model: Understanding disclosure decision making and postdisclosure outcomes among people living with a concealable stigmatized identity', *Psychological Bulletin,* 136 (2), pp.236-256.

Clair, J.A., Beatty, J.E. & MacLean, T.L. (2005) 'Out of Sight but Not Out of Mind: Managing Invisible Social Identities in the Workplace', *Academy of Management Review,* 30 (1), pp.78-95.

Claramonte, M.C. (2016) 'On the noises and rhythms of translation', *Translation & Interpreting Studies: The Journal of the American Translation & Interpreting Studies Association,* 11 (2), pp.131-151.

Closson, E.F., Colby, D. J., Nguyen, T., Cohen, S.S., Biello, K., Mimiaga, M.J. (2015) 'The balancing act: Exploring stigma, economic need and disclosure among male sex workers in Ho Chi Minh City, Vietnam', *Global Public Health*, 10 (4), pp. 520–531.

Cochrane Library (2017) About Cochrane Reviews [Online] Available at: http://www.cochranelibrary.com/about/about-cochrane-systematic-reviews.html (Accessed: 9 October, 2017)

Conyers, L. & Boomer, K.B. (2005) 'Factors associated with disclosure of HIV/AIDS to employers among individuals who use job accommodations and those who do not', *Journal of Vocational Rehabilitation,* 22 (3), pp.189-198.

Conyers, L.M., Richardson, L.A., Datti, P.A., Koch, L.C. & Misrok, M. (2017) 'A Critical Review of Health, Social, and Prevention Outcomes Associated With Employment for People Living With HIV', *AIDS Education and Prevention: Official Publication of the International Society for AIDS Education,* 29 (5), pp.475-490.

Cramer, R.J., Colbourn, S.L., Gemberling, T.M., Graham, J. & Stroud, C.H. (2015) 'Substance-related coping, HIV-related factors, and mental health among an HIV-positive sexual minority community sample', *AIDS Care,* 27 (9), pp.1063-1068.

Crean, M. (2018) 'Minority Scholars and Insider-Outsider Researcher Status: Challenges along a Personal, Professional and Political Continuum', *Forum: Qualitative Social Research,* 19 (1), pp.17.

Creswell (2009) *Research design: qualitative, quantitative, and mixed methods approaches*. 4th edn. London: Sage

Creswell (2013) *Research design: qualitative, quantitative, and mixed methods approaches*. 5th edn. London: Sage

Daly, K. (2000) The business response to HIV/AIDS: Impact and lessons learned [Online] Available at: http://data.unaids.org/publications/irc-pub05/jc445-businessresp_en.pdf (Accessed: 24 April, 2017)

Dankoli, R.S., Aliyu, A.A., Nsubuga, P., Nguku, P., Ossai, O.P., Tukur, D., Ibrahim, L., Madi, J.E., Dalhat, M. & Abdullaziz, M. (2014) 'HIV disclosure status and factors among adult HIV positive patients in a secondary health facility in North-Eastern Nigeria, 2011', *The Pan African Medical Journal,* 18 (1), pp.4-4.

Data Protection (2015) The data protection Act [Online] Available at: https://www.gov.uk/data-protection (Accessed: 25 November, 2017)

Dean, R. (2014) 'Stigmatization and Denormalization as Public Health Policies: Some Kantian Thoughts', *Bioethics,* 28 (8), pp.414-419.

Degroote, S., Vogelaers, D., Koeck, R., Borms, R., De Meulemeester, L. & Vandijck, D. (2014) 'HIV disclosure in the workplace', *Acta Clinica Belgica,* 69 (3), pp.191-193.

Derlega VJ, Metts S, Petronio S, Margulis S.T. (1993) *Self-disclosure*. Sage; Newbury Park, CA.

Eba, P.M. (2015) 'HIV-specific legislation in sub-Saharan Africa: a comprehensive human rights analysis', *African Human Rights Law Journal,* 15 (2), pp.224-262.

Emlet, C.A. (2008) 'Truth and consequences: a qualitative exploration of HIV disclosure in older adults', *AIDS Care,* 20 (6), pp.710-717.

Employment New Zealand (2016) Who is an employee [Online] Available at: http://employment.govt.nz/er/starting/typesofemployment/ (Accessed: 23 May, 2015)

Encyclopaedia Britannica (2007) Oyo state Nigeria [Online] Available at: https://www.britannica.com/place/Oyo-empire (Accessed: 28 February, 2018)

Ezegwui, H.U., Nwogu-Ikojo, E.E., Enwereji, J.O. & Dim, C.C. (2009) 'HIV serostatus disclosure pattern among pregnant women in enugu, nigeria', *J. Biosoc. Sci,* (41), pp.789-798.

Falk, G. (2001) Stigma: how we treat outsiders. New York: Prometheus Books

Federal Ministry of Labour and Productivity (2013) National workplace policy on HIV/AIDS [Online] Available at: http://www.ilo.org/wcmsp5/groups/public/---africa/---ro-addis_ababa/---ilo-abuja/documents/publication/wcms_344217.pdf (Accessed: 16 November, 2017)

Federal Republic of Nigeria Gazette (2014) HIV and AIDS (anti-discrimination law), 2014 [Online] Available at: https://www.ilo.org/wcmsp5/groups/public/---ed_protect/---protrav/---ilo_aids/documents/legaldocument/wcms_444112.pdf (Accessed: 13 November, 2018)

Fesko, S.L. (2001) 'Disclosure of HIV status in the workplace: Considerations and strategies', *Health & Social Work,* 26 (4), pp.235-244.

Fraser, M. & Greco, M. (2005) *Orlan on becoming –Orlan*. Routledge: Oxon

French, H., Greeff, M., Watson, M.J. & Doak, C.M. (2015) 'HIV stigma and disclosure experiences of people living with HIV in an urban and a rural setting', *AIDS Care,* 27 (8), pp.1042-1046.

Frye, V., Fortin, P., MacKenzie, S., Purcell, D., Edwards, L. V., Mitchell, S. G., Latka, M. H. (2009). Managing identity impacts associated with disclosure of HIV status: a qualitative investigation. AIDS Care, 21(8), 1071–1078.

Gidley, B. (2012) ‘Doing historical and documentary research’, in Seale, C. (ed.) researching society and culture. Sage Publication: London, pp. 263-282

Goar, H. (2013) *'Social Stigmas',* in Rosenhan, D. (ed.) Salem Press. pp. 250-258.

Goffman, E. (1968) *Stigma: Notes on the Management of Spoiled Identity*. Harmondsworth: Pelican Books.

Goffman, E. (1963) *Stigma: notes in the management of spoiled identity*. New York: Prentice-Hall.

Gray, D.E. (2013) *Doing research in the real world.* 3rd edn. London: Sage.

Grimwood, A.F., Mothibi, G., Malahlela, E., Shea, M. & Brian, J.E. (eds.) (2012) *Community adherence support improves programme retention in children on antiretroviral treatment: a multicentre cohort study in South Africa.* United States, North America: International AIDS Society.

Groß, M., Herr, A., Hower, M., Kuhlmann, A., Mahlich, J., & Stoll, M. (2016) ‘Unemployment, health, and education of HIV-infected males in Germany’, *International Journal of Public Health*, 61 (no issue), pp. 593–602.

Gubrium, J.F. & Holstein, J.A. (2012) *Narrative Practice and the Transformation of Interview Subjectivity.*United States, North America: e-Publications@Marquette.

Gunter, H., Thomsona, P. & Gunterb, H. (2011) 'Inside, outside, upside down: The fluidity of academic researcher 'identity' in working with/in school', *International Journal of Research and Method in Education,* 34 (1), pp.17-30.

Hamlington, B., Ivey, L.E., Brenna, E., Biesecker, L.G., Biesecker, B.B. & Sapp, J.C. (2015) 'Characterization of Courtesy Stigma Perceived by Parents of Overweight Children with Bardet-Biedl Syndrome', *Plos One,* 10 (10), pp.1-9.

Hayfield, N. & Huxley, C.J. (eds.) (2014) *Insider and outsider perspectives : reflections on researcher identities in research with lesbian and bisexual women.* United Kingdom, Europe: Routledge.

Healthy Working Lives (2013) Chronic illness in the workplace [Online] Available at: http://www.healthyworkinglives.com/advice/workplace-health-promotion/Chronic-Illness (Accessed: 7 May, 2015)

Henderson, C., Brohan, E., Clement, S., Williams, P., Lassman, F., Schauman, O., Murray, J., Murphy, C., Slade, M. & Thornicroft, G. (2012) 'A decision aid to assist decisions on disclosure of mental health status to an employer: protocol for the CORAL exploratory randomised controlled trial', *BMC Psychiatry,* 12 (no issue) pp.133-133.

Hendrickson, S.G., Harrison, T.C., Lopez, N.A., Zegarra-Coronado, A. & Ricks, T. (2013) 'Translation Cost, Quality, and Adequacy', *Journal of Nursing Scholarship,* 45 (2), pp.185-191.

Henry, E., Bernier, A., Lazar, F., Matamba, G., Loukid, M., Bonifaz, C., Diop, S., Otis, J. & Préau, M. (2015) '"Was it a mistake to tell others that you are infected with HIV?": factors associated with regret following HIV disclosure among people living with HIV in five countries (Mali, Morocco, Democratic Republic of the Congo, Ecuador and Romania). Results from a community-based research', *AIDS and Behavior,* 19 (2), pp.311-321.

Hermanns, M. (2013) 'The invisible and visible stigmatization of Parkinson's disease', *Journal of the American Association of Nurse Practitioners,* 25 (10), pp.563-566.

Higgins, J.P.T, Thompson, S.G, Deeks, J.J, Altman DG. (2003) Measuring inconsistency in meta-analyses. *British Medical Journal 327, 557-560*.

HIV Justice Network (2015) Nigeria: Senate Passes Law Criminalising Hiv Non-Disclosure, Exposure And Transmission With Vague And Overly Broad Statutes In The Sexual Offences Bill [Online] Available at: http://www.hivjustice.net/news/nigeria-senate-passes-law-criminalising-hiv-non-disclosure-exposure-and-transmission-with-vague-and-overly-broad-statutes-in-the-sexual-offences-bill/ (Accessed: 4 December 2017).

Hubach, R.D., Dodge, B., Schick, V., Ramos, W.D., Herbenick, D., Li, M.J., Cola, T. & Reece, M. (2015) 'Experiences of HIV-positive gay, bisexual and other men who have sex with men residing in relatively rural areas', Culture, Health & Sexuality, 17 (7), pp.795-809.

Husebø, S.E., O'Regan, S. & Nestel, D. (2015) 'Theory for Simulation: Reflective Practice and Its Role in Simulation', *Clinical Simulation in Nursing,* 11 (no issue), pp.368-375.

Inhetveen, K. (2012) 'Translation Challenges: Qualitative Interviewing in a Multi-Lingual Field', *Qualitative Sociology Review,* 8 (2), pp.28-45.

International Labour Office (ILO) (2014) International labour standards by subject [Online] Available at: https://www.ilo.org/wcmsp5/groups/public/---ed_norm/---normes/documents/genericdocument/wcms_230305.pdf (Accessed: 12 November, 2018)

International Labour Office (ILO) (2001) An ILO code of practice on HIV/AIDS and the world of work [Online] Available at: https://www.ilo.org/wcmsp5/groups/public/@ed_protect/@protrav/@ilo_aids/documents/publication/wcms_113783.pdf (Accessed: 27 October, 2018)

Jahn, W. T. (2011) 'The 4 basic ethical principles that apply to forensic activities are respect for autonomy, beneficence, nonmaleficence, and justice', *Journal of Chiropractic Medicine,* 10 (3), pp.225-226.

Janahi, E.M., Mustafa, S., Alsari, S., Al-Mannai, M. & Farhat, G.N. (2016) 'Public knowledge, perceptions, and attitudes towards HIV/AIDS in Bahrain: A cross-sectional study', *Journal of Infection in Developing Countries,* 10 (9), pp.1003-1011.

Jans, L.H., Kaye, H.S. & Jones, E.C. (2012) 'Getting Hired: Successfully Employed People with Disabilities Offer Advice on Disclosure, Interviewing, and Job Search', *Journal of Occupational Rehabilitation,* 22 (2), pp.155-165.

John, W.S. & Johnson, P. (2000) 'The Pros and Cons of Data Analysis Software for Qualitative Research', *Journal of Nursing Scholarship,* 32 (4), pp.393-397.

Johnson, H., Lavesson, N., Zhao, H. & Wu, S.F. (2011) *'On the Concept of Trust in Online Social Networks',* in Anonymous Springer. pp. 143-157.

Joint United Nations Programme on HIV/AIDS (UNAIDS) (2015) Guidelines on monitoring the impact of the HIV epidemic using population-based surveys, UNAIDS/WHO working group on global HIV/AIDS and STI surveillance [Online] Available at : http://www.unaids.org/sites/default/files/media_asset/JC2763_PopulationBasedSurveys_en.pdf (Accessed: 20 April, 2016)

Jones, K.P. & King, E.B. (2014) 'Managing Concealable Stigmas at Work: A Review and Multilevel Model', *Journal of Management,* 40 (5), pp.1466.

Jugdeo, N. (2009) Exploring HIV/AIDS stigma in the workplace: voice of the stigmatised. Masters of Art. Univesity of South Africa.

Kaler, A., Angotti, N. & Ramaiya, A. (2016) 'They are looking just the same: Antiretroviral treatment as social danger in rural Malawi', *Social Science & Medicine,* 167 pp.71-78.

Kalichman, S., Hernandez, D., Kegler, C., Cherry, C., Kalichman, M. & Grebler, T. (2015) 'Dimensions of poverty and health outcomes among people living with HIV infection: limited resources and competing needs', *Journal of Community Health,* 40 (4), pp.702-708.

Kalichman, S.C. (1995) Understanding AIDS: A guide for mental health professionals, *American Psychological Association*; Washington, DC.

Katherine, H. (2000) 'Making the invisible, visible', *Journal of Child Health Care,* 4 (3), pp.123-126.

Kerstetter, K. (2012) 'Insider, outsider, or somewhere in between: the impact of researchers' identities on the community-based research process', *Journal of Rural Social Sciences*, 27(2), pp. 99–117.

Koch, T. , Kralik, D. and Eastwood, S. (2002) 'Constructions of sexuality for women living with multiple sclerosis', *Journal of Advanced Nursing*, 39: 137-145

Komiti, A, Judd. F., Grech, P., Mijch, A., Hoy, J., Lloyd J.H., Street, A. (2001) Suicidal Behaviour in People with HIV/AIDS: A Review *Aust N Z J Psychiatry,* 35(6), pp747-57

Korte, R.F. (2007) 'A review of social identity theory with implications for training and development', *Journal of European Industrial Training,* 31 (3), pp.166-180.

Kothari, C.R. (2004) Research Methodology: Methods and Techniques. 2nd Edn, New Age International Publishers: New Delhi.

Lee, S., Yamazaki, M., Harris, D.R., Harper, G.W. & Ellen, J. (2015) 'Social support and human immunodeficiency virus-status disclosure to friends and family: Implications for human immunodeficiency virus-positive youth', *Journal of Adolescent Health,* 57 (1), pp.73-80.

Legarth, R., Lars Haukali, O., Gitte, K., Carsten S., L., Court, P., Gitte, P., Ulrik Bak, D., Jan, G. & Niels, O. (2014) 'Employment status in persons with and without HIV infection in Denmark: 1996–2011', *Aids,* 28 (10), pp.1489-1498.

Lever, A. & Wainberg, M. (2015) 'World AIDS Day 2015', *Retrovirology,* 12 pp.101-101.

Li, X., Li, X., Qiao, S., de Wit, J. & Sherr, L. (2015) 'What's in the telling? Understanding social, psychological and clinical aspects of HIV disclosure', *Aids Care-Psychological and Socio-Medical Aspects of AIDS/HIV,* 27 pp.1-5.

Lim, V.K.G. & Loo, G.L. (2000) 'HIV and the workplace: Organisational consequences of hiring persons with HIV and attitudes towards disclosure of HIV-related information', *International Journal of Manpower,* 1(2), pp.129.

Liu, Y., Canada, K., Shi, K. & Corrigan, P. (2012) 'HIV-related stigma acting as predictors of unemployment of people living with HIV/AIDS', *AIDS Care,* 24 (1), pp.129-135.

Lu, Y. & Gatua, M.W. (2014) 'Methodological Considerations for Qualitative Research with Immigrant Populations: Lessons from Two Studies', *Qualitative Report,* 19 (30), pp.1-16.

Lundberg, P.C., Doan, T.T.K., Dinh, T.T.X., Oach, N.K. & Le, P.H. (2016) 'Caregiving to persons living with HIV/AIDS: experiences of Vietnamese family members', *Journal of Clinical Nursing,* (5-6), pp.788-798.

Lyimo, R.A., Stutterheim, S.E., Hospers, H.J., de Glee, T., Van, D.V. & de Bruin, M. (2014) 'Stigma, Disclosure, Coping, and Medication Adherence Among People Living with HIV/AIDS in Northern Tanzania', *AIDS Patient Care & STDs,* 28 (2), pp.98-105.

Lynch, J.W. & Rodell, J.B. (2018) 'Blend in or stand out? Interpersonal outcomes of managing concealable stigmas at work', *Journal of Applied Psychology.*

MacRae, H. (1999) 'Managing courtesy stigma: the case of Alzheimer's disease', *Sociology of Health & Illness,* 21 (1), pp.54-70.

Makhado, L., Davhana-Maselesele, M., Golekanye, K.M., Koboekae, N.W., Keria, D.O., Maraka, M.M., Mfebe, C.N. & Rathulong, K.V. (2015) 'Nurses' perspective regarding disclosure of human immune virus status in the workplace, Limpopo province', *African Journal for Physical, Health Education, Recreation & Dance,* 21 (1), pp.292-299.

Marshall, B., Cardon, P., Poddar, A., Fontenot, R. (2013) Does sample size matter in qualitative research?: a review of qualitative interviews in is research. *Journal of Computer Information Systems, 51(1), pp. 11-22*

Masoudnia, E. (2015) 'Public perceptions about HIV/AIDS and discriminatory attitudes toward people living with acquired immunodeficiency syndrome in Iran', *SAHARA-J: Journal of Social Aspects of HIV / AIDS,* 12 (1), pp.116-122.

Mayfield Arnold, E., Rice, E., Flannery, D. & Rotheram-Borus, M. (2008) 'HIV disclosure among adults living with HIV', *AIDS Care,* 20 (1), pp.80-92.

McDonald, K., Slavin, S., Pitts, M.K. & Elliott, J.H. (2016) 'Chronic Disease Self-Management by People With HIV', Qual Health Res, 26 (6), pp.863-870.

McLeod, S.A. (2008) Social Identity Theory [Online] Available at: https://www.simplypsychology.org/social-identity-theory.html (Accessed: 16 July, 2017).

McMahon, S. (2003) 'Disclosing HIV in the workplace. One personal perspective from the corporate world', *The Body Positive,* 16 (4), pp.19-20.

McNeill, F.G. (2009) Condoms cause AIDS: Poison, prevention and denial in Venda, South Africa. African Affairs, 108(432), 353370. da, South Africa. African Affairs, 108(432), 353370.

Merton, R.K. (1968) *Social theory and social structure*. Toronto: The Free Press

Michael Borenstein, L. V. Hedges, J. P. T. Higgins and H. R. Rothstein (2009) Introduction to Meta-Analysis. John Wiley & Sons, Ltd

Miell, D. & Dollas, R. (1996) Social interraction and personal relationships. Reading: Sage Publications.

Monjok, E., Smesny, A., & Essien, E. J. (2009) HIV/AIDS - Related Stigma and Discrimination in Nigeria: Review of Research Studies and future directions for Prevention Strategies. *African Journal of Reproductive Health*, *13*(3), 21–35.

Moore, D., D. (ed.) (2015) *Experience of Being an Insider and an Outsider during a Qualitative Study with Men Who Have Experienced Significant Weight Loss.* United States, North America: NSUWorks.

Mugisha, J., Scholten, F., Owilla, S., Naidoo, N., Seeley, J., Chatterji, S., Kowal, P. & Boerma, T. (2013) 'Caregiving responsibilities and burden among older people by HIV status and other determinants in Uganda', *AIDS Care,* 25 (11), pp.1341-1348.

Muhimbuura, A.L., Eric, S., Sarah, S., Christopher, T., Nicolate, N., Annette, N., Gery, R. & Glenn, W. (2014) 'HIV/AIDS status disclosure increases support, behavioural change and, HIV prevention in the long term: a case for an Urban Clinic, Kampala, Uganda', *BMC Health Services Research,* 14 (1), pp.661-679.

Murray, M. & Chamberlain, K. (1999) Qualitative Health Psychology. London: Sage Publications

Musumali, R.M. (2012) HIV disclosure in the workplace amongst public service workers in Zambia. University of the Western Cape.

Nachega, J.B., Adetokunboh, O., Uthman, O.A., Knowlton, A.W., Altice, F.L., Schechter, M., Galárraga, O., Geng, E., Peltzer, K., Chang, L.W., Cutsem, G.V., Jaffar, S.S., Ford, N., Mellins, C.A., Remien, R.H. & Mills, E.J. (2016) 'Community-Based Interventions to Improve and Sustain Antiretroviral Therapy Adherence, Retention in HIV Care and Clinical Outcomes in Low- and Middle-Income Countries for Achieving the UNAIDS 90-90-90 Targets', *Curr HIV/AIDS Rep,* 13 (5), pp.241-255.

Nasidi, A & Harry, T. O (2006) The epidemiology of HIV/AIDS in Nigeria O. Adeyi, P.J. Kanki, O. Odutolu, J.A. Idoko (Eds.), AIDS in Nigeria: A Nation on the Threshold, Harvard Center for Population and Development Studies, Cambridge (Massachusetts) (2006) Available: http://www.apin.harvard.edu/Chapter2.pdf (Accessed: 16 May, 2016)

National Agency for the Control of AIDS (NACA) (2015) Federal Republic of Nigeria Global AIDS Response Country Progress Report Nigeria GARPR 2015 [Online] Available at: http://www.unaids.org/sites/default/files/country/documents/NGA_narrative_report_2015.pdf (Accessed: 16 May, 2016)

National AIDS Trust (2016) Advice for Employee living with HIV [Online]. Available at: http://www.nat.org.uk/Media%20library/Files/Policy/2010/5180-NAT-A5-HIV-Work-Employees.pdf (Accessed: 25 May, 2016).

National Policy on HIV/AIDS (NPHA), (2009) 'National policy on HIV/AIDS' [Online] Available at: http://nigeria.unfpa.org/pdf/ntpol.pdf (Accessed: 26th October, 2014).

Nattabi, B., Li, J., Thompson, S.C., Orach, C.G. & Earnest, J. (2011) 'Factors Associated With Perceived Stigma Among People Living With HIV/AIDS in Post-Conflict Northern Uganda', *AIDS Education & Prevention,* 23 (3), pp.193-205.

Nemakanga, M.N. & Mndzebele, S.L. (2015) 'Life experiences and circumstances surrounding elderly people living with HIV and AIDS in Northern Gauteng, South Africa: perspectives of HIV and AIDS across populations', *African Journal for Physical Health Education, Recreation and Dance,* pp.88.

NHS Choices (2018) Advice for employees on working with a long-term medical condition [Online] Available at: https://www.nhs.uk/Livewell/workplacehealth/Documents/ChronicConds_Employees_Factsheet_A4.pdf (Accessed: 29 October, 2018)

Niu, L., Luo, D., Liu, Y., Silenzio, V.M.B. & Xiao, S. (2016) 'The Mental Health of People Living with HIV in China, 1998–2014: A Systematic Review', *Plos One,* 11 (4), pp.1-18.

Obermeyer, C. M., Baijal, P., & Pegurri, E. (2011). Facilitating HIV Disclosure Across Diverse Settings: A Review. *American Journal of Public Health*, *101*(6), 1011–1023.

Odimegwu, C., Adedini, S.A. & Ononokpono, D.N. (2013) 'HIV/AIDS stigma and utilization of voluntary counselling and testing in Nigeria', *BMC Public Health,* 13 (1), pp.1-14.

Ogoina, D., Ikuabe, P., Ebuenyi, I., Harry, T., Inatimi, O. & Chukwueke, O. (2015) 'Types and predictors of partner reactions to HIV status disclosure among HIVinfected adult Nigerians in a tertiary hospital in the Niger Delta', *African Health Sciences,* 15 (1), pp.10-18.

Okareh, O.T., Akpa, O.M., Okunlola, J.O. & Okoror, T.A. (2013) 'Management of Conflicts Arising From Disclosure of HIV Status Among Married Women in Southwest Nigeria', *Health Care for Women International*.

Olagbuji, B.N., Ezeanochie, M.C., Agholor, K.N., Olagbuji, Y.W., Ande, A.B. & Okonofua, F.E. (2011) 'Spousal disclosure of HIV serostatus among women attending antenatal care in urban nigeria', *Journal of Obstetrics and Gynaecology: The Journal of the Institute of Obstetrics and Gynaecology,* 31 (6), pp.486-488.

Olalekan Orija, S. & Samuel Oyekale, A. (2012) 'Stigma, discrimination and willingness to buy vegetables from people living with HVI&AIDS (PLWHA) in rural Nigeria', Life Science Journal, 9 (4), pp.2094-2100.

Olley, B.O. (2007) 'The role of support group and duration of infection in HIV/AIDS patients' knowledge and attitudes to their illness', Afr J Med Med Sci, 36 (1), pp. 11-16.

Oloruntoba-Oju, T. (2011) 'Sexuality indices in Yoruba language and popular culture / Taiwo Oju-Oloruntoba', *Sexuality in Africa Magazine & Monographs,* 7 (2), pp.14-20.

Olsen W. (2004) Triangulation in social research: qualitative and quantitative methods can really be mixed. *Developments in sociology* 20: 103-118.

Ortblad, K.F., Lozano, R. & Murray, C.J.L. (2013) 'The burden of HIV: insights from the global burden of disease study 2010', *Aids,* 27 (13), pp.2003-2017.

Palmer, R.T. (2015) 'Examining the Prevalence of Poor Help-Seeking Behavior among Black Men at Historically Black Colleges and Universities', *Culture, Society & Masculinities,* 7 (1), pp.33-44.

Parfene, C., Stewart, T.L. & King, T.Z. (2009) 'Epilepsy stigma and stigma by association in the workplace', *Epilepsy and Behavior,* 15 (4), pp.461-466.

Parkhurst, J.O. (2010) 'Understanding the correlations between wealth, poverty and human immunodeficiency virus infection in African countries', *Bulletin of the World Health Organization,* 88 (7), pp.519-526.

Pascoe, S.J.S., Langhaug, L.F., Mavhu, W., Hargreaves, J., Jaffar, S., Hayes, R. & Cowan, F.M. (2015) 'Poverty, Food Insufficiency and HIV Infection and Sexual Behaviour among Young Rural Zimbabwean Women', *Plos One,* 10 (1), pp.1-21.

Patterson, S. E., Milloy, M.-J., Ogilvie, G., Greene, S., Nicholson, V., Vonn, M., … Kaida, A. (2015). The impact of criminalization of HIV non-disclosure on the healthcare engagement of women living with HIV in Canada: a comprehensive review of the evidence. *Journal of the International AIDS Society*, *18*(1), 20572.

Peckham, M. (1991) Research and Development for the National Health Service. *Lancet*, 338, 367-371.

Peter, L.Y. (2011) The experiences of transport sector employees after their disclosure of living with HIV in the workplace [Online]. Available at: http://repository.up.ac.za/dspace/bitstream/handle/2263/29630/dissertation.pdf?sequence=1&isAllowed=y (Accessed: 25 May, 2016)

Phella, Bloch & Seale (2012) 'Structured methods: interviews, questionnaire and observation', in Seale, C. (ed.) Researching society and culture. Sage Publication: London, pp. 181-205.

Phillips, K., Rothbard, N., & Dumas, T. (2009). To Disclose or Not to Disclose? Status Distance and Self-Disclosure in Diverse Environments. *The Academy of Management Review*, 34(4), 710-732.

Phillips, R., Benoit, C., Hallgrimsdottir, H. & Vallance, K. (2012) 'Courtesy stigma: a hidden health concern among front-line service providers to sex workers', *Sociology of Health & Illness (Print),* 34 (5), pp.681-696.

Pietrangelo, A. (2004) The Effects of HIV on the Body [Online] Available at: http://www.healthline.com/health/hiv-aids/effects-on-body (Accessed: 25 May, 2016).

Poudel, A.N., Newlands, D. & Simkhada, P. (2017) 'The economic burden of HIV/AIDS on individuals and households in Nepal: a quantitative study', *BMC Health Services Research,* 17 pp.1-13.

Poudel, A.N., Newlands, D. & Simkhada, P.P. (2016) *Issues and Problems in Conducting Sensitive Research: A Case of HIV/AIDS in Nepal.*United Kingdom, Europe: Nepal Public Health Students Society.

Rahmati-Najarkolaei, F., Pakpour, A.H., Saffari, M., Hosseini, M.S., Hajizadeh, F. & Chen, H. & Yekaninejad, M. S. (2017) 'Determinants of lifestyle behavior in Iranian adults with prediabetes: Applying the theory of planned behavior', Archives of Iranian Medicine, 20 (4), pp.198-204.

Rao, D., Angell, B., Lam, C. & Corrigan, P. (2008) 'Stigma in the workplace: Employer attitudes about people with HIV in Beijing, Hong Kong, and Chicago', *Social Science & Medicine,* 67 (10), pp.1541-1549.

Regmi, K., Naidoo, J. & Pilkington, P. (2010) 'Understanding the processes of translation and transliteration in qualitative research', *International Journal of Qualitative Methods,* 9 (1), pp.16-26.

Rivas, C. (2012) 'Coding and analysing qualitative data', in Seale, C. (ed.) Researching society and culture. Sage Publication: London, pp. 393-404

Robertson, P.J. (2014) 'Health inequality and careers', *British Journal of Guidance & Counselling,* 42 (3), pp.338-351.

Rodkjaer, L., Chesney, M.A., Lomborg, K., Ostergaard, L., Laursen, T. & Sodemann, M. (2014) 'HIV-infected individuals with high coping self-efficacy are less likely to report depressive symptoms: a cross-sectional study from Denmark', *International Journal of Infectious Diseases,* 22 pp.67-72.

Rosen, S., Simon, J., Vincent, J.R., Wiliam, M., Fox, M., & Thea, D. (2003) AIDS is your Business [Online] Available at: https://hbr.org/2003/02/aids-is-your-business (Accessed: 23/06/2015)

Ross, M.W., Essien, E.J. & Torres, I. (2006) 'Conspiracy beliefs about the origin of HIV/AIDS in four racial/ethnic groups', *Journal of Acquired Immune Deficiency Syndromes (1999),* 41 (3), pp.342-344.

Rother, E.T. (2007) 'Systematic literature review X narrative review', *Acta Paulista De Enfermagem,* 20 (2), pp.5-6v-vi.

Rotzinger, A., Locatelli, I., Reymermier, M., Amico, S., Bugnon, O., Cavassini, M. & Schneider, M.P. (2016) 'Association of disclosure of HIV status with medication adherence', *Patient Education and Counseling,* 99 pp.1413-1420.

Rözer, J.J. & Volker, B. (2016) 'Does income inequality have lasting effects on health and trust?', *Social Science & Medicine,* 149 pp.37-45.

Saal, K., Martinez, L.R. & Smith, N.A. (2014) 'Visible disabilities: Acknowledging the utility of acknowledgment', *Industrial and Organizational Psychology: Perspectives on Science and Practice,* 7 (2), pp.242-248.

Sadoh, W.E. & Sadoh, A.E. (2009) 'Experiences of HIV positive mothers who chose not to breastfeed their babies in Nigeria: original research article', *African Journal of Reproductive Health,* 13 (1), pp.27-35.

Sagay A.S., Musa J., Ekwempu C.C., Imade, G.E., Babalola A., Daniyan G., Malu, N., Idoko J.A. & Kanki P.(2006) 'Partner disclosure of HIV status among HIV positive mothers in northern nigeria', *African Journal of Medical Science,* 35(1)119-231.

Sage, M. & Joseph, D. (2015) 'Visible and invisible identities', *Campus Activities Programming,* 47 (6), pp.22-25.

Salami, A.K., Fadeyi, A., Ogunmodede, J.A. & Desalu, O.O. (2011) 'Status disclosure among people living with HIV/AIDS in Ilorin, Nigeria', *West African Journal of Medicine,* 30 (5), pp.359-363.

Seale, C. (2012) Researching society and culture 3rd edn Sage Publication: London

Sekoni, A.O., Obidike, O.R. & Balogun, M.R. (2012) 'Stigma, medication adherence and coping mechanism among people living with HIV attending general hospital, lagos island, Nigeria/Stigmatisation, observance', *African Journal of Primary Health Care & Family Medicine, 4* (1), pp.1-10.

Senyalo, R.G., Maja, T. & Ramukumba, T.S. (2015) 'Stigma experienced by people living with HIV and AIDS in Soshanguve, South Africa', *African Journal for Physical Health Education, Recreation and Dance,* 21 (1), pp.94-106.

Serovich, J. M. (2001) 'A test of two HIV disclosure theories', *AIDS Education and Prevention : Official Publication of the International Society for AIDS Education*, *13*(4), 355–364.

Serovich, J. M., & Mosack, K. E. (2003) Reasons for HIV disclosure or nondisclosure to casual sexual partners. *AIDS education and prevention: official publication of the International Society for AIDS Education*, 15(1), 70-80.

Serovich, J.M., Lim, J. & Mason, T.L. (2008) 'A retest of two HIV disclosure theories: the women's story', *Health & Social Work,* 33 (1), pp.23-31.

Sidney, M.J. (1971) Bibliography [Online] Available at: http://www.sidneyjourard.com/ (Accessed: 7 May 2015).

Sigelman, C.K., Howell, J.L., Cornell, D.P., Cutright, J.D. & Dewey, J.C. (1991) 'Courtesy Stigma: The Social Implications of Associating With a Gay Person', *Journal of Social Psychology,* 131 (1), pp.45-56.

Silverman, D. (2012) 'Giving oral presentation', in Seale, C. (ed.) Researching society and culture. Sage Publication: London, pp. 519-525.

Silverman, D. (2013) Interpreting qualitative data. London: Sage

Simpson, E. & Jones, M. (2013) 'An exploration of self-efficacy and self-management in COPD patients', *British Journal of Nursing,* 22 (19), pp.1105-1109.

Smith (2009) Interpretative Phenomenological Analysis [Online] Available at: http://www.cmpcp.ac.uk/JASSlides.pdf (Accessed: 6 May, 2015)

Smith, R., Rossetto, K. & Peterson, B. (2007) 'A meta-analysis of perceived stigma, disclosure of one's HIV + status, and perceived social support', *Conference Papers -- National Communication Association,* pp.1 Available at: http://0-eds.b.ebscohost.com.brum.beds.ac.uk/eds/pdfviewer/pdfviewer?vid=2&sid=ca0790d1-7084-4883-8e06-431298db939e%40sessionmgr102 (Accesssed: 27 June, 2017).

Sonya Corbin, D. & Buckle, J.L. (2009) 'The Space Between: On Being an Insider-Outsider in Qualitative Research', *International Journal of Qualitative Methods,* 8 (1), pp.54-63.

Ssali, S.N., Atuyambe, L., Tumwine, C., Segujja, E., Nekesa, N., Nannungi, A., Ryan, G. & Wagner, G. (2010) 'Reasons for disclosure of HIV status by people living with HIV/AIDS and in HIV care in Uganda: an exploratory study', *AIDS Patient Care & STDs,* 24 (10), pp.675-681.

Starr, M., Chalmers, I., Clarke, M., Oxman, A.D., Starr, M., Chalmers, I., Clarke, M. & Oxman, A.D. (2009) 'The origins, evolution, and future of The Cochrane Database of Systematic Reviews', *International Journal of Technology Assessment in Health Care,* 25 (1), pp.182-195.

Stolley and Glass (2009) HIV/AIDS England: Greenwood Press [Online] Available at: http://reader.vlebooks.com/reader/open?accId=10402&cite=1&isbn=9780313344220&maxCopy=24&maxPrint=24&mmLimit=0&notes=1&pageLimit=0&shareLink=%2F%2FWWW.VLEBOOKS.COM%2FVLEWEB%2FPRODUCT%2FINDEX%2F152742&startPage=0&timestamp=2016-05-20T18%3A08%3A04&userId=604635&watermark=++++++++++++++++++++++++++++++BEDSUNI%2FWMXMQWC2RMVRMDFKBJJJUMSWV0FMTLZ0IC9NPQ++++++++++++++++++++++++++++++&token=4PkHQF2Fn2HMMWDT7m%2fraRKoB4M%3d (Accessed: 20 May, 2016).

Tajfel, H. & Turner, J. C. (1979). 'An Integrative Theory of Intergroup Conflict'. In W. G. Austin & S. Worchel (Eds.), The Social Psychology of Intergroup Relations. Monterey, CA: Brooks-Cole.

Tam, V., Pharris, A., Thorson, A., Alfven, T. & Larsson, M. (2011) 'It is not that I forget, it's just that I don't want other people to know': barriers to and strategies for adherence to antiretroviral therapy among HIV patients in Northern Vietnam', *AIDS Care,* 23 (2), pp.139-145.

Taylor, D., Bury, M., Campling, N., Carter, S., Garfied, S., Newbould, J. & Rennie, T. (2006). A Review of the use of the Health BeliefModel (HBM), the Theory of Reasoned Action (TRA),

the Theory of Planned Behaviour (TPB) and the Trans-Theoretical Model (TTM) to study and predict health related behaviour change. [Online] Available at: https://www.nice.org.uk/guidance/ph6/resources/behaviour-change-taylor-et-al-models-review2 (Accessed: 28 February, 2018).

Tenkorang, E.Y. (2013) 'Myths and misconceptions about HIV transmission in Ghana: what are the drivers?', *Culture, Health & Sexuality,* 15 (3), pp.296-310.

The Critical Appraisal Skills Programme [CASP] (2013) Eleven questions to help you make sense of case control study [Online] Available at: http://docs.wixstatic.com/ugd/dded87_afbfc99848f64537a53826e1f5b30b5c.pdf (Accessed: 23 October, 2017)

The Nigeria Ministry of Labour and Productivity (2013) National workplace policy on HIV and AIDS [Online] Available at: http://www.labour.gov.ng/Doc/NATIONAL_WORKPLACE_POLICY_ON_HIV_AND_AIDS.pdf (Accessed: 27 February, 2017)

Titilope, A. A., Adediran, A., Umeh, C., Akinbami, A., Unigwe, O., & Akanmu, A. S. (2011). Psychosocial Impact of disclosure of HIV Serostatus in heterosexual relationship at the Lagos University teaching Hospital, Nigeria.*Nigerian Medical Journal : Journal of the Nigeria Medical Association*, *52*(1), 55–59.

Toth, K. & Dewa, C. (2014) 'Employee Decision-Making About Disclosure of a Mental Disorder at Work', *Journal of Occupational Rehabilitation,* 24 (4), pp.732-746.

Tracey, P. & Phillips, N. (2016) 'Managing the Consequences of Organizational Stigmatization: Identity Work in a Social Enterprise', *Academy of Management Journal,* 59 (3), pp.740-765.

Trepte, S. (ed.) (2006) *Social identity theory.* Blackwell: Routledge New York.

Tsai, A.C., Bangsberg, D.R., Bwana, M., Haberer, J.E., Frongillo, E.A., Muzoora, C., Kumbakumba, E., Hunt, P.W., Martin, J.N. & Weiser, S.D. (2013) 'How does antiretroviral treatment attenuate the stigma of HIV? Evidence from a cohort study in rural Uganda', *AIDS and Behavior,* 17 (8), pp.2725-2731.

Tshuma, N., Mosikare, O., Yun, J.A., Alaba, O.A., Maheedhariah, M.S., Muloongo, K. & Nyasulu, P.S. (2017) 'Acceptability of community-based adherence clubs among health facility

staff in South Africa: a qualitative study', *Patient Preference and Adherence, Vol Volume 11, Pp 1523-1531 (2017),* 11 pp. 1523-1531.

Tyson, M., Covey, J. & Rosenthal, H.E.S. (2014) 'Theory of planned behaviour interventions for reducing heterosexual risk behaviours: A meta-analysis', *Health Psychology,* Available at: http://0-eds.b.ebscohost.com.brum.beds.ac.uk/eds/pdfviewer/pdfviewer?sid=d4536167-5f94-41c3-9ccd-b8b9fd3e15a8%40sessionmgr113&vid=2&hid=107 (Accessed: 29 May 2014).

Tzouvara, V., Papadopoulos, C. & Randhawa, G. (2015) 'A narrative review of the theoretical foundations of loneliness', *British Journal of Community Nursing,* 20 (7), pp.329-334.

Ubesie, A.C., Iloh, K.K., Emodi, I.J., Ibeziako, N.S., Obumneme-Anyim, I., Iloh, O.N., Ayuk, A.C., Anikene, C.J. & Enemuo, J.E. (2016) 'HIV status disclosure rate and reasons for non-disclosure among infected children and adolescents in Enugu, southeast Nigeria', *SAHARA-J: Journal of Social Aspects of HIV/AIDS,* 13 (1), pp.136-141.

Udoma, U. & Belo-Osagie (2015) Data Privacy Protection in Nigeria [Online] Available at: http://www.uubo.org/downloads/SIMM0715001-Data_Privacy_Protection_in_Nigeria.pdf (Accessed: 25 November, 2017)

Ujah, I.A.O., Ezechi, O.C. & Ohihoin, A.G. (2015) 'HIV Status Discordance: Associated Factors Among HIV Positive Pregnant Women in Lagos, Southwest Nigeria', *African Journal of Reproductive Health,* 19 (2), pp.108-116.

Umesh, S.J., Deepali, S.D., Sonali, G.C., Vilas, R.M. & Harshada, M.U. (2013) 'Human immunodeficiency virus serostatus disclosure-Rate, reactions, and discrimination': A cross-sectional study at a rural tertiary care hospital', *Indian Journal of Dermatology, Venereology and Leprology, Vol 79, Iss 1, Pp 135-135 (2013),* 79 (1), pp.135-135.

UNAIDS (2000) The Business Response to HIV/AIDS: Impact and lessons learned [Online] Available at: http://data.unaids.org/publications/irc-pub05/jc445-businessresp_en.pdf (Accessed: 25 May, 2016).

UNAIDS (2014) How AIDS changed everything [Online] Available at: http://www.unaids.org/en/resources/campaigns/HowAIDSchangedeverything/factsheet (Accessed: 14 August, 2015)

UNAIDS (2015) AIDS by number 2015 [Online] Available at: http://www.unaids.org/sites/default/files/media_asset/AIDS_by_the_numbers_2015_en.pdf (Accessed: 21 March, 2017)

UNAIDS (2016) Global AIDS Response Progress Reporting [Online] Available at: http://www.unaids.org/sites/default/files/media_asset/2016_GARPR_reporting_overview_en.pdf (Accessed: 16 May, 2016)

UNAIDS (2017) Nigeria [Online] Available at: http://www.unaids.org/en/regionscountries/countries/nigeria (Accessed: 12 December, 2017)

UNAIDS (2017) 90-90-90: an ambitious treatment target to help end the AIDS epidemic [Online] Available at: http://www.unaids.org/en/resources/909090 (Accessed: 10 July, 2018)

UNAIDS Gap report (2014) Voluntary confidential counselling and testing at work [Online] Available at: http://www.ilo.org/wcmsp5/groups/public/---ed_protect/---protrav/---ilo_aids/documents/image/wcms_329145.pdf (Accessed: 2 January, 2017)

United Nations Department of Economic and Social Affairs/Population Division (UNDESA/PD) (2016) The Impact of AIDS [Online] Available at: http://www.un.org/esa/population/publications/AIDSimpact/7_Chap_IV.pdf (Accessed: 25 May, 2016).

University of Bedfordshire (2014) Discover [Online] Available at: http://lrweb.beds.ac.uk/digital/discover (Accessed: 4 December 2014)

Vergnes, J.N., Marchal-Sixou, C., Nabet, C., Maret, D. & Hamel, O. (2010) 'Ethics in systematic reviews', *Journal of Medical Ethics,* 36 (12), pp.771-774.

Wagstaff, C. & Williams, B. (2014) 'Specific design features of an interpretative phenomenological analysis study', *Nurse Researcher,* 21 (3), pp.8-12.

Walsh, D. (2012) 'Doing ethnography', in Seale, C. (ed.) Researching society and culture. Sage Publication: London, pp. 245-262.

Wang, X., Guo, J., Zhang, X., Qu, Z., Tian, D. & Ma, S. (2014) 'Original Research: The effects of depression and chronic diseases on the work outcomes of employees: a prospective study in Northwest China', *Public Health,* 128 pp.734-742.

Weihs, M. & Meyer-Weitz, A. (2016) 'Barriers to workplace HIV testing in South Africa: a systematic review of the literature', *AIDS Care,* 28 (4), pp.495-499.

Weiner, B., Perry, R.P. & Magnusson, J. (1988) *An attributional analysis of reactions to stigmas.* New York: American Psychological Association, Inc.

Williams, C.L. (2016) Interreligious encounter in a West African city: a study of multiple religious belonging and identity among the Yorùbá of Ogbómòsó, Nigeria. University of Edinburgh.

Worchel, S., Morales, J.F., Paez, D. & Deschamps, J. (1998) Social identity: international perspectives. London: Sage Publication.

World Health Organisation (2017) HIV/AIDS [Online] Available at: http://www.who.int/mediacentre/factsheets/fs360/en/ (Accessed: 21 November, 2017)

World Health Organisation (WHO) (2010a) Breast is always best, even for HIV-positive mothers [Online] Available at: http://www.who.int/bulletin/volumes/88/1/10-030110/en/ (Accessed: 23 May, 2016)

World Health Organisation (WHO) (2010b) Archived: Guidelines on HIV and infant feeding 2010 Principles and recommendations for infant feeding in the context of HIV and a summary of evidence [Online] Available at: http://www.who.int/maternal_child_adolescent/documents/9789241599535/en/ (Accessed: 20 June, 2017)

World Health Organisation (WHO), (2014a) HIV/AIDS [Online] Available at: http://www.who.int/hiv/en/ (Accessed: 10 January, 2015)

World Health Organisation (WHO), (2014b) Public comments on the global validation advisory committee nominations [Online] Available at: http://www.who.int/mediacentre/factsheets/fs360/en/ (Accessed: 05 May 2015)

Wray, J. (2015) Why undertake pilot work in a qualitative PhD study? Lessons learnt to promote success [Online] Available at: https://my.rcn.org.uk/__data/assets/pdf_file/0019/622135/2015-research-4.1.2.pdf (Accessed: 29 October, 2017)

Wu, X., Chen, J., Huang, H., Liu, Z., Li, X. & Wang, H. (2015) 'Perceived stigma, medical social support and quality of life among people living with HIV/AIDS in Hunan, China', *Applied Nursing Research,* 28 (2), pp.169-174.

Xia, X. (2016) 'Typology and the translation of interpersonal meaning', *Theory and Practice in Language Studies,* 6 (6), pp.1300-1304.

Yonah, G., Fredrick, F. & Leyna, G. (2014) 'HIV serostatus disclosure among people living with HIV/AIDS in Mwanza, Tanzania', *AIDS Research and Therapy,* 11 (1), pp.1-11.).

Yuh, J.N., Ellwanger, K., Potts, L. & Ssenyonga, J. (2014) 'Stigma among HIV/AIDS Patients in Africa: A critical Review', *Procedia - Social and Behavioral Sciences,* 140 pp.581-585.

Zou, J., Yamanaka, Y., John, M., Watt, M., Ostermann, J. & Thielman, N. (2009) 'Religion and HIV in Tanzania: Influence of religious beliefs on HIV stigma, disclosure, and treatment attitudes', *BMC Public Health,* 9 pp.1-12.

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Appendices

Appendix 1: Participant Information Sheet

My name is Dorcas Ibukun Adeoye. I am a research student studying at the University of Bedfordshire, UK. My research project explores the impact of HIV disclosure in the workplace

among people living with HIV/AIDS in Nigeria. I will be conducting a one-to-one interview with you to collect information about your experience. Before you agree to participate please read this information sheet carefully, make sure you understand the information and ask me any questions.

What will I have to do if I take part?

If you agree to take part, I will ask you to answer a number of questions on this topic. There aren't any right or wrong answers and you don't need to do any preparation for this interview. We just want to hear your opinions and experience.

How long will the interview take?

The interview will take approximately one hour and it will be organised with you in advance in an appropriate time and location.

Do I have to take part?

No, **taking part is voluntary**. If you don't want to take part, you do not have to give a reason and no pressure will be out on you to try and change your mind. You can pull out of the interview at any time without giving any reasons. Please note, if you choose not to participate, or you pull out during the interview this will **not** affect you in any way.

If I agree to take part what happens to information I provide?

All the information you give me **will be kept confidential** and will be used for the purposes of this study only. The data collected will be stored in accordance with the UK Data Protection Act 1998 and will be disposed of or deleted within five years of data collection. The information will be used in a way that will not allow you to be identified individually.

Will I be paid for my time?

Participation in this interview is voluntary and you will not be paid for your time. However, a soft drink will be provided.

What do I do now?

Think about the information on this sheet, and ask me if you are not sure about anything. If you agree to take part, please sign the consent form. The consent form will not be used to identify you. It will be filed separately from all other information. If, after the interview, you want any more information about the study, you can contact me and you can also contact the Director of Studies with any complaint, with the contact details below.

Complaints procedures:

If you have any complains about this study, please contact my Director of Studies, Dr. Hala Evans at Hala.Evans@beds.ac.uk,Tel: 0158-2743-783. For more information on the study, please contact me: Ms Dorcas Adeoye at dorcas.adeoye@study.beds.ac.uk, Tel: 0744020xxxx

THANK YOU VERY MUCH FOR YOUR HELP!

Iwe Alaye Olukopa

Orukọ mi ni Dorcas Ibukun Adeoye. Mo jẹ ọmọ-akẹkọ iwadi ti n kekọ ni Univasity Bedfordshire, UK. Ise iwadi mi ṣawari ikolu ti ifihan HIV nse ni ibi iṣẹ laarin awọn eniyan ti o ngbe pẹlu HIV / AIDS ni Nigeria. Un yoo ṣe apejuwe ijomitoro oro enikan-si-enikan pẹlu yin lati gba alaye nipa iriri yin. Ṣaaju ki e to gba lati kopa, e jọwọ e ka iwe ipamọ yii ni pẹlẹpẹlẹ, ki e si rii daju pe alaye yii ye yin, e si le beere ibeere eyikeyi lọwọ mi.

Nkan kini mo ni lati ṣe bi mo ba yan lati kopa?

Ti e ba gba lati kopa, emi yoo ni ki e dahun awon ibere lori koko eko yii. Ko si idahun ti o to na tabi ti ko to na, ati pe o ko nilo lati ṣe eyikeyi igbaradi fun ijomitoro yii. Mo kan fẹ lati gbọ ero ati iriri yin ni.

***Akoko wo ni ijomitoro yii yoo gba*?**

Ijomitoro oro yii yoo gba to wakati kan, ati pe ao ṣeto pẹlu yin saawaju saju akoko naa nipa igba ati ibi ti o rorun fun yin.

Nje mo ni lati kopa?

Rara! Ikopa ni lati je atinuwa. Ti e ko ba fẹ lati kopa, e ko ni lati fun mi ni idi kankan, ati pe nko ni gbiyanju lati yi ero ọkan yin pada. E le fa kuro ninu ijomitoro yii ni igbakugba laisi fifunni ni iidi. E jọwọ e ṣe akiyesi wipe, ti e ba yan lati ko kopa, tabi ti e fa jade lakoko ibere ijomitoro yii, kii yoo ni ipa lori yin ni ọna eyikeyi.

Ti mo ba yan lati kopa, kini ohun ti yoo ṣẹlẹ si alaye ti mo pese?

Gbogbo alaye ti e fun mi ni maa pamọ ni asiri, ati pe un o lo fun idi iwadi yii nikan. Awọn esi ti mo gba ni un o tọju ni ibamu pẹlu Ofin Idaabobo Esi Ifoworo woro UK 1998, ati pe yoo wa ni pipaarẹ laarin ọdun marun i gbigba esi. Un o lo awon esi ti mob a gba ni ọna ti kii yoo si lati mo yin ni olukuluku.

Njẹ ao san owo fun mi fun akoko mi?

Ijomitoro oro yii jẹ atinuwa ati pe un ko ni sanwo fun akoko rẹ. Sibẹsibẹ, n o pese ohun mimu fun yin.

Ohun wo ni moni lati ṣe bayi?

E wo awon alaye ti o wa lori iwe yii, ki e si beere lọwọ mi bi e ko ba ni idaniloju nipa ohunkohun. Ti e ba gba lati kopa, e jọwọ e fowosi fọọmu ifowosowopo. A ki yoo lo fọọmu naa lati ṣe

idanimọ yin. N yoo ko soto kuro laarin gbogbo alaye miiran. Lẹhin ijomitoro, ti e ba fẹ alaye diẹ sii nipa iwadi yii, e le kan si mi ati pe e tun le kan si Oludari Ẹkọ pẹlu eyikeyi ẹdun, pẹlu awọn alaye olubasọrọ.

Awọn ilana ẹdun ọkan: Ti e ba ni ẹdun kan nipa iwadi yii, e jọwọ e kan si Oludari Eko, Dokita Hala Evans ni Hala.Evans @ beds.ac.uk, Waya: 0158-2743-783. Fun alaye miran sii lori iwadi, e jọwọ e kan si mi: Ms Dorcas Adeoye ni dorcas.adeoye@study.beds.ac.uk, Waya: (+44)07440203634

E SE FUN IRANLOWO YIN

Appendix 2: Interview materials

Appendix 2a: Interview schedule

HIV/AIDS DISCLOSURE IN THE WORKPLACE IN NIGERIA: A QUALITATIVE STUDY

INTERVIEW SCHEDULE

1. Preliminaries and Building rapport

Hello, how are you. Thanks for agreeing to talk to me. I hope you are alright. Are you coming directly from work? What is the nature of the work that you currently do? How life is it at work?

I understand you were tested positive recently, would you mind telling me when that was? So how has it been since then?

2. **Living experience, disclosure and its implications**

Please tell me how life is it with family and friends?

Could you please share with me your experience of telling others your condition? Who did you tell?

(a) **Family**- who in the family? Why? Why not others? When? What were the reasons for telling them? How was it? What impacts does it have? Why did you choose this way? What was the reaction of the person (s) you talked to? Did you tell them yourself? To What extent? With the help of someone? Or other person told them? Were you aware? What impact does this have on you?

(b) **Friend(s)-** Why? When? What was your relationship with the person? What were the reasons for telling them? Do you have other friends? Why not other friends? What was the reaction of person (s) you talked to? Did you tell them yourself? With the help of someone? Or other person told them? Were you aware? What impact does this have on you?

4. **Workplace Disclosure and factors influencing disclosure**

Did you tell your work colleague, employer, or anyone in your workplace? Does your employer have HIV policies (including confidentiality provisions)?

(a) (**Yes**) Can you tell me about your experience of telling people about your HIV status in your workplace? Who have you told about your HIV status? Why? When? What were the reasons for telling them? What was the position of the person (s)? How has your employer responded to you informing them of your HIV status? How did they react? Has informing them impacted on your workplace experience, if so, in what way? What Policies does your organisation have to support employees with HIV? How are these policies implemented in practice?

(b) (**No**): why don't you tell anyone in your workplace? Has anyone disclosed on your behalf? Who? What was the position of the person? What was your reaction? Can you tell me some concerns/worries related to telling others about your status in your workplace? Has your decision had any impact on how stressed you feel? Has it had any impact on how isolated you feel or caused you any regret? Will you consider telling someone in your workplace? Who, in case you change your mind in future? What could encourage you to tell someone in future?

(c) Have you experienced post disclosure breaches of confidence (perhaps whether it involved friends, family, colleagues or others)

5. Socio-demographic information

Can you tell me more about yourself (where are you from? your level of education)?

Additional information

Is there anything that I have not asked about the topic that you feel it would be important to the study?

***Thank participant for their contribution, stress confidentiality.**

Siso Nipa Kokoro AIDS anti ile ise ti e ti nsise ni NIGERIA: Iwadii ni fininfinin.

Iseto Iforoworo

1. *Awọn asọtẹlẹ ati Imora eni.*

   E pele o, bawo ni o? . E ṣeun fun gbigba lati sọrọ pelu mi. Mo nireti pe gbogbo nkan lo daradara? Nje e n bọ lati iṣẹ ni? Kini iru iṣẹ ti e nṣe lọwọlọwọ? Bawo ni igbesi aye yin nibi iṣẹ? Mo mọ pe won ni e ni kokoro kogboogun ni aipe yii, ṣe e le sọ fun mi bi gbogbo nkan tinlo lati gba naa? Nitorina bawo ni e ti wa lati igba naa?

2. *Awọn iriri igbesi aye, ifihan ati awọn idiyele rẹ*

Nje e le so fun mi lọwọlowo bi igbesi aye yin ṣe wa pẹlu awọn ẹbi ati awọn ọrẹ?

E jowo e pin iriri yin pelu mi bi e ti sọ fun awọn elomiran ni ipo rẹ ti e wa? Ta ni e sọ?

(A) Ìdílé- tani ninu ẹbi? Kí nìdí? Kilode ti kii se elomiran? Nigbawo? Kini awọn idi ti e fi sọ fun wọn? Bawo ni e se ri? Ipa wo ni o ni? Kini idi ti e fi yan ọna yii? Kini aiṣe ti eniyan ti o sọrọ si? Ṣe o sọ funrararẹ ara rẹ? Ni Iwọn wo? Pẹlu iranlọwọ ẹnikan bi? Tabi eniyan miiran ti won sọ fun wọn? Ṣe o mọ? Ipa wo ni eyi ni lori rẹ?

(B) Awon Ọrẹ - Kí nìdí? Nigbawo? Kini ibasepọ yin pẹlu eniyan naa? Kini awọn idi ti e fi sọ fun wọn? Ṣe e ni awọn ọrẹ miiran? Kilode ti awọn ọrẹ miiran ko se mo? Kini iyọ ti eniyan ti o sọrọ si? Ṣe e sọ funrararẹ ara rẹ? Pẹlu iranlọwọ ẹnikan bi? Tabi eniyan miiran lo sọ fun wọn? Ṣe o mọ? Ipa wo ni eyi ni lori rẹ?

3. *Ifihan lenu iṣẹ ati awọn okunfa ti o ni ipa ifihan*.

Nje e sọ fun alabaṣiṣẹpọ yin, agbanisiṣẹ, tabi ẹnikẹni nibi iṣẹ yin? Ṣe agbanisiṣẹ yin ni awọn ipilẹṣẹ HIV (pẹlu awọn ipamọ igbekele)?

(A) (Bẹẹni). Ṣe e le sọ fun mi nipa iriri rẹ nipa sisọ fun eniyan nipa ipo HIV yin ni ibi iṣẹ rẹ? Ta ni o ti sọ nipa ipolowo HIV yin? Kí nìdí? Nigbawo? Kini awọn idi ti e fi sọ fun wọn? Kini ipo ti eniyan naa? Bawo ni agbanisiṣẹ yin ṣe dahun si yin lati sọ fun wọn nipa ipo e ni kokoro HIV? Bawo ni wọn ṣe? Nje e ti ṣe alaye fun wọn lori i iriri yin, bi o ba je bẹ, ni ọna wo? Awọn imulo wo ni ajo yin ṣe lati ṣe atilẹyin fun awọn alaṣẹ ti o ni kokoro HIV? Bawo ni a ṣe ṣe awọn imulo wọnyi ni ibi iṣe?

(B) (Bẹẹkọ): Kilode ti e ko sọ fun ẹnikẹni ninu iṣẹ rẹ? Njẹ ẹnikan ti sọ fun yin? Ta ni? Kini ipo ti eniyan naa? Kini iṣe rẹ? Ṣe e le sọ fun mi diẹ ninu awọn ifiyesi / awọn iṣoro ti e ni ibatan si sisọ awọn elomiran nipa ipo rẹ ni ibi iṣẹ rẹ? Njẹ ipinnu yin ni ipa lori bi o ṣe jẹ ki o lero? Njẹ e ni ikolu lori bi e ṣe sọtọ ti o nro tabi ti o ṣe iyọnu fun yin? Ṣe eyin yoo so fun ẹnikan ni iṣẹ yin lojo waju? Tani? Kini o le ṣe iwuri fun yin lati sọ fun ẹnikan ni ojo iwaju?

C) **Nję o ti ni iriri ipolowo nini kokoro yii (boya o ję awọn ọrę, ębi, awọn alabaṣiṣę tabi awọn miran).**

4. *Awọn alaye ti ara-ęni-ara-ęni:*

Nje e lesọ fun mi diẹ sii nipa ara ryin (nibo ni e ti wa? Ipele ękọ yin)?

Appendix 2b: Sample of a coded transcript

PARTICIPANT – 010

VENUE- BOWEN TEACHING HOSPITAL

Duration: Aprox. 26mins 24secs

BRIEF DEMOGRAPHIC INFORMATION: Full-time chief clerical officer, diagnosed for more than 10yrs, Married, Male; partner's status is positive.

LANGUAGE: Yoruba with mix of English

ACRONYMS USED: I- Interviewer; P-participant n-number e.g 1,2,3 etc.

I: How are you now?

P10: I actually don't feel bad and I'm very okay

I: How were you told about your condition at first?

P10: That time, I was sick and was referred to Prof. XX's clinic and they did the test. After the test, I was referred to UCH and that is where I am talking treatment from 2005 till now.

I: When you were told, how do you feel?

P10: I felt somehow because when they told me, I said why? Why me? but when things happened, there is nothing you can do because when there is life, there is hope.

I: Who told you and how did they relate the information to you?

P10: The counsellor in that place

I: Is it like a hospital or clinic?

P10: No it's like a CCT referral centre

I: Did you just go there or how?

P10: I was referred to the place from my workplace. It was my boss that told me to go to the workplace health centre and from there, I was referred to that CCT referral centre. I think they have conducted the test, so they referred me to the place to be confirmed. When they told me, I felt bad but when I started treatment, I realised that its not something that would kill me and there is nothing in this earth that doesn't have solution. There are some other diseases that are more chronic than this one we are talking about.

I: Who did you tell after you know about this?

P10: Apart from my boss in the office, except for my wife and I told her after I had recovered very well. When I recovered very well, I took her to the hospital and she also had the test then we discovered she is also infected and we went to the referral centre and she was also refereed to UCH. That is where she is also receiving treatment and in the middle of this, we had as we having to have a child for long. She came for another Antenatal now and that why I said it also brought good to us.

Comment [DA1]: SYMPTOMS/SIGNS OF DIAGNOSIS: was sick

Comment [DA2]: LENGTH OF DIAGNOSIS: 11 years

Comment [DA3]: REACTION AFTER AWARENESS: felt somehow, surprised

Comment [DA4]: COPING MECHANISM: powerless, left with no choice, there is life there is hope

Comment [DA5]: WHO TOLD YOU: the counsellor

Comment [DA6]: SUPPORT: refereed for treatment, boss advise to have a test

Comment [DA7]: REACTION AFTER AWARENESS: felt bad

Comment [DA8]: COPING MECHANISM: realise HIV can't kill me, everything has a solution, there are more chronic disease than this

Comment [DA9]: HIV AS A PHENOMENON: more diseases are more chronic than HIV

Comment [DA10]: WHO KNOWS: my boss

Comment [DA11]: WHO KNOWS: my wife

Comment [DA12]: FACTORS INFLUENCING DISCLOSURE: after I recovered

Comment [DA13]: PARTNER'S STATUS: positive status

Comment [DA14]: POSITIVE EXPERIENCE AFTER BEING DIAGNOSED: had a child we've long waited for, HIV brought us good

Appendix 2c: Summary of the codes generated

Aim 2: Explore the perceptions of disclosure among employed people living with HIV/AIDS in Nigeria			
Objective 1a: Discuss the factors that influence people living with HIV/AIDS in Nigeria to disclose in their workplace			
Sub-theme	Code	Sub-code	Data
Personality	Level of knowledge	Knowledge of HIV	*people that have knowledge can be told than people that don't have the knowledge (P02) *person who is knowledgeable (P03) *I don't think so because we understand this thing differently and we that are affected understand it but people that don't have it may not understand it and they think that people that are close to death or ready to die are the ones that are infected with HIV (P15)
		Character	*not just someone that… look at you somehow (P03)

			*I have been thinking that I needed to tell him but I am not sure the kind of person he is maybe he will expose me (P03) *not a person that will talk to you or destroy your reputation (P03)
		Expose me	*Thinking that I needed to tell him but… he may expose me (P03)
	Timing	Right time to disclose	*I said I will but I have not yet, I am still giving it's thought (P03)
Support	Expectations to render help	They are not ready to help, have some help to render	* I am not ready to tell anybody because they are not ready to help (P06) *I told her to tell my state of health maybe he may also have some help to render (P10) *People that knows are …people that will take care of me if I have any problem (P10)
	Poverty	Financial ability	*If God provided for me more than this, I can do anything

	Health Improvement	Physical look	*I will encourage the person and say look at me, can you believe I have it, many of them don't believe me (P03)
		Similar HIV status	*Yes they know… we work together, we are the same (P02)
Level of Relationship	Work Relationship	Inform doctors that work with us	*I used to inform every new doctor that works with us (P01)
		Similar work/department	*We don't work together, except we are working in the same department and working together (P01)
	Closeness/intimacy	Close to me	*People that knows are people that are close to me (P10)
Duty of care	Newly diagnosed who needs counselling	Need to counsel newly diagnosed, counselling unwilling person to start treatment	*If they bring someone and I know that person needs treatment and care… I will use myself as an example (P01) *I used to tell people esp. the newly diagnosed (P03)

	Trust	Lack of trust	*…I am the one that told her… because I know they will still tell her somehow (P01)
		Trust	*When you know that this person won't tell anyone, you can tell them (P02) *she did not abandon me, because she is the only one I can trust (P10)
	Nature of job	related job	*When the programme started that was when many people know; we bring them here and talk to them (P01)
	Workplace requirement	Compulsory HIV testing before resuming job	*they tell us to get tested even here before accepting my application but I told them I have it, so I don't need to do it again. I always tell them I have it so I don't waste my money again doing the test (P03). * For here, they must [test everyone]. I found favour, you know, if it is somewhere else, because of that, they may not give you the job again (P04)

Objective 1b: Discuss the factors that influence people living with HIV/AIDS in Nigeria not to disclose in their workplace			
Sub-theme	Code	Sub-code	Data
Fear	Unknown outcome/consequences	Fear of disappointment	*the heart of people can't be seen. If you trust the person and the person disappointed me, it's up to him/her (P04) *If someone says we are friends like a brother, it's a lie; it's a lie. No matter how you know how to do it there will be a day you will disagree and the secret you keep with the person will be an instrument of fight to use for me (P08)
	Level of knowledge	Public understanding of HIV	*Some think sitting together, you can be infected… or sitting together in the same vehicle (P01)
Personality	Lack of trust, misconception	Insufficient knowledge of the person's	*I have been thinking that I need to tell him but I am not sure the kind of person he is maybe he will expose me outside (P03) *I don't think so because we understand this thing differently and we that are affected understand it

			but people that don't have it may not understand it and they think that people that are close to death or ready to die are the ones that are infected with HIV (P15)
	To avoid embarrassment	Staying away from embarrassment	* what will I do, if that is the best way of staying away from embarrassment, or doing anything (P05)
	To avoid hatred	There must be hatred	* there must be hatred, you know and I will not do anything to affect anyone (P07)
	Depression	It will make me depressed	* It will make me depressed… and may quicken my death. They will run away and that will make it too much and if you are lonely or alone every day, the person will die soon (P16)
	Death	Quicken my death, loneliness	* It may quicken my death. They will run away and that will make it too much and if you are lonely or alone every day, the person will die soon (P16)

Trust	Expose me	Lack of trust, Not able to keep secret	*I have been thinking that I need to tell him but I am not sure the kind of person he is maybe he will expose me outside (P03) *when someone cannot keep their mouth shut, you can't tell (P03) * I don't think that day will come because we are all human and we can't trust someone that the person can't betray us (P15)
	Betray me	Human beings can expose and betray me	** I don't think that day will come because we are all human and we can't trust someone that the person can't betray us (P15)
Health Status	Health improvement, No sign of HIV infection, healing/recovery	No sickness/symptoms	*I don't fall sick and I won't and there is no symptoms showing (P04). *No benefit [of disclosure] … when someone doesn't have problem (P04) *I rang my boss on Saturday that I won't be coming to work on Monday that I was sick and he asked if

			no problem, I said I had little malaria… I resumed on Wednesday, so when they noticed how I was feeling, they told me to go back home and return to school when I am perfectly okay so since then that I noticed I have recovered; I didn't feel weak or vomit again, no one asked me anything again (P15) *Never, I can't tell anyone and nobody will know, my appearance isn't bad and since I have being using my drugs, I haven't come to complain of any other thing (P17)
	Good physical look, unbelief, adherence to treatment	HIV not physically seen, good appearance	*I have a lot of them (bosses) but they haven't noticed anything (P03) *If I tell them, they won't believe me…The fact is that if they can believe because when you look healthier than somebody who... [don't have HIV] (P09)

			*When people see me, they will know that I am healthy and also taking my drugs regularly. No one will notice anything (P12) **Never, I can't tell anyone and nobody will know, my appearance isn't bad and since I have being using my drugs, I haven't come to complain of any other thing (P17)
Relationship	Level of relationship	Not living together, cant disclose to an outsider	*No danger at all since we don't live together nor eat together. Everyone is where they are supposed to be (P04) *No, if I cannot tell my mother that born me, I cannot disclose to other outsider (P11)
Anticipated negative consequences of disclosure	Loss of privacy	Uncontrolled spread of information	*The danger is that they may start talking about me everywhere (P04) * If you tell someone, everyone in this town will know and it is even better if you decide to go on radio and advertise yourself. The person will tell

			everybody that this person is having this and that, and this is what is affecting her. So, you can't just tell someone (P03) *Some people, when you tell them they may react somehow and tell everyone that, 'you see that people don't move close to because he/she's got AIDS' (P07) * I can't say it at work [sighs in], someone has put herself as an object of discussion…they start saying, you better not move close to her, she's got this and that. So, I can't say anything (P12) * No, I can't say it, never because God has healed me and if I say it, it's as if I am selling myself for people (P17)
	Gossip, loss of friendship	They gossip a lot	*I don't think it is a good idea…they gossip a lot.. So to just avoid this thing, one has to behave himself (P05)

			*The reason why I left the place is not that they make fun of me but they may start talking (P13)
Isolation & Avoidance	Social Isolation	Not be close to me, Running away from me	* They may not be close to me as before; that's just it (P04) *It's when you tell somebody, as in, they will select you one side, running away from you as if something is going to… is contagious definitely and you know in working sector like this, everyone wants to protect his/her own individual (P05) * I can't say it at work [sighs in]… people would run away from me and they start saying, you better not move close to her, she's got this and that (P12) * The reason why I left the place is not that they make fun of me. If I touch something, they don't want to touch it or if I use a plate, they may not use it again. So they believe that may get infected

			through plate or clothe when my body touches them (P13) * They may run away from me. I have some people we talk, chat and do things together but they may run away from me saying I have this and that (P16)
Support	Support gained without disclosure	My boss gives me permission for my appointment, ease attending hospital appointment, being accepted and embraced, good work relationship	*When I wanted to feel tired, I will take permission, I will tell my boss at work and she will tell me to go and rest and if I go to Ibadan, and because I didn't disclose to them what is wrong with me, I will just tell them…she would say, you can go, no problem…She doesn't bother; she won't ask me what I'm going there for…sometimes, she may visit me in my home (P07) *When it started, it was on a Friday, so I rang my boss on Saturday that I won't be coming to work on Monday that I was sick and he asked if no problem, I said I had little malaria. So when I didn't go to

			school [work] on Monday and Tuesday, so I resumed on Wednesday, so when they noticed how I was feeling, they told me to go back home and return to school when I am perfectly okay (P15) * I will say I am going for check-up but I don't tell them what I go there for except for my wife, no one knows anything… [from] my boss…[they] never asked me [what sort of check-up I go for] (P16) * You know when I had the sickness, my boss in Ibadan and here knows when I had to be off at work for about 4 months and we needed to call them that I was sick. I said I was sick but they didn't know it was this thing (P17) * The last time I was on leave and I noticed my lap is paining me so I massaged it gently with a cream. So I called because I was to resume on Friday but they told me to come on Monday and they told me

			it's because I have not been doing lots of exercise by walking, that's the reason and we joked over it (P17) *Even where I work, they didn't behave any how when they told me to come monthly and I will ring the boss that I needed to go for check-up. Even they transferred some senior officers some days ago and they have also informed him that I go for check-up monthly (P17)
Confidentiality in the workplace	Limited access to medical records, procedure is followed	Procedures is followed to protect medical records	* it has procedures they follow, when you get your card, the doctor will attend to you and they know when they need to return it to (P04)
	Access to medical report	Penalty for bridging confidentiality	* We are in a hospital, not everything you see, you talk about…For someone that now says what he is not supposed to say…if the management hears about it, they can sack you (P04)

			* Here, you dear not because Mama must not here such, they will lose their job (P06)
	Negative experience of others	Making fun of some PLWHA	* Some people say they will make fun of him/her. There was someone, she said before, she was selling fried yam and Akara and bread… so they had quarrel and the man sent her away and used her status against her. Immediately, every neighbourhood knows and because of that shame, she left the area to another place (P07)
	Agreement of keeping the secret within the family	They made it secret	*I may not [disclosure at workplace] because when that happened to me, he kept the secret and no one in his [husband] family up till date, no one knows about it (P07) *No, if I cannot tell my mother that born me, I cannot disclose to other outsider (P11)
Nature of job	Type of job	Shift work pattern	*You know my type of work is shift pattern. When I have my appointment when I'm off work, I don't

			have to inform them so they don't have to know every time (P16) *I'm close for night duty, I just take my bag, I don't sleep, I have to come for the clinic which I have to go back night shift, that one for sure (P05) *I may go to work early about 7:30 to do what I needed to do and sign, then leave but I won't return till the next day (P17)
Objective 1c: Discuss the factors that influence people living with HIV/AIDS in Nigeria to disclose in future in their workplace			
Sub-theme	Code	Sub-code	Data
Absenteeism	Difficulty attending regular appointment, time consuming	Can't go to work [on appointment day]	*I can't go to work that day and leave later, I have to leave the whole day for me to go for the bleeding; I can't divide myself. So, there is no way, I will have to tell [my] boss (P03). *It [check-up] takes a bit of time (P11)
HIV management	Fear of missing appointment	Affect missing appointment	*I may not be thinking of telling him if not that it will affect missing my appointment date (P03)

Employee's Reputation	Protecting work reputation, transparency	Obligation to open to boss	*I wanted to tell him and he would know and that will not be new to him and thinking I am taking a day off for other unnecessary things (P03)
Relationship	Length of relationship	Trusted person in a long relationship	*Some people behave that we may conclude that I trust this person and I am sure he/she can't do this, and it would have been a long relationship (P04)
Personality	Character of the recipient, evaluation of character	Check the life of the person	* if you want to tell the person, check the life of the person and know his/her faith and if the person can keep secret, someone can tell the person (P07)
Trust	Keeping secret		* if you want to tell the person, check the life of the person and know his/her faith and if the person can keep secret, someone can tell the person (P07)
Newly diagnosed, opens up	Similar HIV status who opens up	If the person has it and opens up	*If the person now got tested and the person came to me and say, thank you and you see this is what actually happened to me, and then I would say, I also have it…it's because the person came out clean that's why I'm telling him (P08)

	Similar HIV status who agree to go through treatment	If the person agrees to start treatment	* I can't tell anybody except if I see that the person has the same problem I have and I saw the person, talked to the person and put him/her through... When he/she agrees to go through treatment, I will now come out to her (P07)
Support		Gives time (permission to go for check-up)	*He used to give me time when I needed it (without disclosing one's status) (P03)
Objectives 2a: Understand to whom those living with HIV/AIDS disclose to in their workplace, and why			
Sub-theme	Code	Sub-code	Data
	Health professionals	*doctors whose work is relevant here *nurses, auxiliary nurses know *doctors seen frequently	*I used to inform every new doctor that works with us in this unit that their work is relevant here and they attend to our people here; I used to tell them (P01) *Everyone working with us, nurses, auxiliary nurses; they all know (P01)

			*the doctors in our (workplace health centre) medical centre, I can't keep my status from them… I open up to doctors I see frequently (P010)
	Work colleagues	work colleagues know	*yes they [work colleagues] know (P02) *The person that also knows is the person working in the same workplace and we leave in the same house (P06)
Unit Head	Unit Head, Senior Colleagues	My senior colleagues knows	* I will tell my senior colleagues, and since they know, I will say I am going for check-up. I don't have any problem (P06)
Line Manager	Manager	I told my boss	*I told my boss (P10)
	Work researcher	Prof. knows	*The person that also knows (at my workplace) is Prof. X (P10)
Objectives 2ai: **Understand to whom those living with HIV/AIDS plan to disclose to in their workplace**			
Sub-theme	Code	Sub-code	Data
	My boss	I need to tell him	*I have been thinking that I need to tell him (P03)
Objectives 2b: Understand why disclosure in their workplace (to that person)			

Type of Relationship	Work relationship	doctors whose work is relevant here, colleague working together	*I used to inform every new doctor that works with us in this unit that their work is relevant here and they attend to our people here; I used to tell them (P01) *We work together here but she is an axillary nurse (P06)
Medical assistance	Medical assistance	Doctors can help to recommend drugs	*the doctors in our (workplace health centre) medical centre, I can't keep my status from them… because they may help me with identifying and recommending drugs that is good for me (P010)
Clinical trial involvement, research purpose	volunteered as one of the participants	volunteered as one participant of a clinical trial	* The person that also knows (at my workplace) is Prof. X because he is involved in HIV drug and I was one of those that volunteered when testing the drug in 2006 (P10)
Counselling, nature of job	Counselling PLWHA	*counsel them to adhere to treatment	*I used to tell them (PLWHA) in the meeting that I am not using any other drug; it is this same drug I

			am using. Let everyone of you use their drugs according to how it is prescribed (P01)
Care & support	Gives me attention	She gives me attention and welcomed me	*whenever I go to her for help, she doesn't look at me with such eye due to what I have experienced. The attention she gives me is more than the one before I had the condition. It's like she liked me more (P10)
	Trust & Reliance	She is trusted and didn't abandon me	*she did not abandon me, because she is the only one that I can trust (P10)
Objectives 2bi: Understand why disclosure in their workplace (to that person) in future			
Sub-theme	Code	Sub-code	Data
Management of status in the workplace	Free to manage status	Encourage me to manage my condition	*I will just tell him [my boss], I want to go and do this and he will say go, so I will be free (P03)
	Free to gain permission	Easy to gain permission	*I will just tell him [my boss], I want to go and do this and he will say go, so I will be free (P03)

			* I will tell my senior colleagues, and since they know, I will say I am going for check-up. I don't have any problem (P06) * I have thought about that towards my boss. So that anytime I request for opportunity to go for my appointment, he will give me (P11)
		Difficulty to gain permission	* Sometimes, he will refuse, he will shout on me. So, it comes to my mind that I will tell him (P11)
	Free from keeping secret	Telling them to be free	*I should tell him [boss], so I will be free. I should tell him, so I won't be bothered about what lie will I present again this time (P03)
Objective 3ai: Examine the psychological impact and practical implications of disclosure in the workplace for people living with HIV/AIDS			
Sub-theme	Code	Sub-code	Data
Emotional reaction	Shame, disgrace	Shouting and disgracing me, I am seriously ashamed	*he came to my workplace and started shouting and disgracing me…you know its workplace, all my colleague and people that came for other things...

			You know I will be ashamed and I can't withstand such. (P13)
Emotional distress	Cry	It made me cry	*You know such spreads easily…if I give them anything, the plate may be thrown away or they throw the food away. So those things made me cry (P13)
	Abandonment	He abandoned me	*there is nothing, he has abandoned me, I am pregnant and I am the one taking care of myself (P13)
Limiting future disclosure	Negative outcome of disclosure	If people again, it will be a shame	* I didn't inform anyone except my mum and people that we meet together here for medication, no other person because if people know again, it will be a shame for me (P13)

	Thought of death	It's like I should die	*It's like I should die (P13)
Suicidal behaviour	Suicidal thought	I want to swallow battery and die	*So it's as if I should swallow something I die,… there was a day I wanted to swallow a used battery. I went to buy a cold coke-cola and take it with it. And that I should lock myself up and die and they will carry my corpse (P13)
	Indifference	I don't bother	*colleagues pretend not to know… I don't even bother as long as they can't confront me (P01)
		It's their cup of tea	* You see, if they sense [that I have HIV], that's their own cup of tea (P06)
Isolation	Social Isolation, effect on close relations	People avoiding my friends, avoiding people I socialise with	*Sometimes ago, they don't relate with our boss here, they will say because we socialise together (P01)
Inclusion	Social inclusion	I still go to her and we interact	* I'm no longer working under her but I still go to her and we interact, sometimes, she would call me,

			…those kind of people, you can't be far from them, that's why (P10)
	Gossip	Don't bother about their talks	*I don't even bother as long as they can't confront me (P01)
		Making fun of me	*when I first started my job here, some people make fun of me (P01) *people that lived with me, if I take something, they will start making fun of me (P13)
Trust	Trust, security	Lack of trust, feeling secured	*Anything can happen and there is nothing human being cannot do (P03) *You know such spreads easily and if someone should hear it… If something is a secret and you tell someone, the person will tell another person and it continues that way (P13) * I don't think that day will come because we are all human and we can't trust someone that the person can't betray us (P15)

	Discrimination	Support	*they are trying and they don't discriminate against us and we trust them (P02)
Management of HIV	Support	Liberty to take permission	*they give me permission even if I need to go to school, I will take permission and they give me
	Support	Ease to request for permission	*they give me permission even if I need to go to school, I will take permission and they will give me (P02)
Knowledge of HIV	Knowledge of HIV	Confidence to counsel	*I use to tell them in the meeting that I am not using other drug… let everyone use their drugs (P01) *I will encourage the person and say look at me, can you believe I have it, many of them don't believe me (P03)
Knowledge of HIV	Inclusion, respect	Professional knowledge of health workers	*Our doctors and nurses don't do anything of such. They usually give us full respect and they don't discriminate against you (P01)
	Campaign	Confidence to campaign	* I get involved in lots of programme even in the radio and television, what is the big deal. They

			know, they know, I have been involved in a programme organised by the governor's wife (P01)
Loss of privacy	Loss of privacy	Uncontrolled spread of information, third-party disclosure without consent	* Everyone knows although, they may not be able to say it but they know (P01) *You know such spreads easily and if someone should hear it… If something is a secret and you tell someone, the person will tell another person and it continues that way, so that was what caused it (P13) *It's possible they tell another person and that it was the reason why I am not at work (P13)
	Change of location	I left Ibadan to Ogbomosho	*he came to disgrace me there and people that don't know anything about it were there so it led to shame for me that's why I moved to Ogbomosho (P13)
	Absenteeism	Left my job	* It's about 5 months [I left my job] (P13)

Support	Support of newly diagnosed patients	counselling newly diagnosed, advising on following prescribed drugs	*I used to tell them in the meeting that I am not using any other drug; it is this same drug I am using. Let everyone of you use their drugs according to how it is prescribed.
Employment opportunity	Job opportunities	Got job after the sickness	*I didn't look for job here when they gave me job… my former boss said please come and advise patients and I continue (P01) *they said they needed someone that can use herself to counsel others and use herself as example, they employed me (P06)
	Difficulty getting job	They won't give you job if your status is known	*For people to know that you have this condition, they won't give you job and that shouldn't happen. For someone that has this condition, and educated …they will not offer the person job because of what

			the person have, and that feeling may cause something (P03)
	Left my job	Left my job after he disgraced me at work	* the person that knows about my condition went to my workplace and disgraced me, so that's why I am home now and I left that job (P13)
Poverty	Financial inability	They struggle to eat because they have this illness	* People having this illness, will still be struggling to eat and it is a condition that you need to eat a good diet and take care of yourself but if there is no means, the person will eat anything that comes his/her way (P03)
Care & support	Gives me attention	She gives me attention and welcomed me	*whenever I go to her for help, she doesn't look at me with such eye due to what I have experienced. The attention she gives me is more than the one before I had the condition. It's like she liked me more (P10)
	Financial support	She gave me money and feed my family	* When it happened, I didn't have money to do some things, she was the one giving me some

			stipends, feed my family before they pay my salary… she took loan for me to complete it [my house] (P10)
Objective 3b: Examine the psychological impact and practical implications of non-disclosure in the workplace for people living with HIV/AIDS			
Sub-theme	Code	Sub-code	Data
Management of status	Management of status, absenteeism, supportive environment	Supportive environment	*I had to tell my boss that I am receiving treatment in Xx and he used to give me chance (time of work) *Most time, I do lie because I don't want them to know... and my boss is very nice, he will give me chance (P15)
		Difficulty requesting for hospital permission regularly	*It is very difficult for me to leave that time, I still need to go to my boss and explain (P03)

			*If I go every month to collect it, they will be suspicious and asked what I go there for, every month (P07) * Sometimes, he will refuse, he will shout on me…after a while, I will tell him again because he may be angry at that time and he will calm down (P11) *I would have to excuse myself from work to submit my card here and be sitting down, it's not easy (P11) * I may say I want to go to town and you know it will be difficult to say…if I tell them I want to go to hospital, they understand I may want to visit someone but between the space of 2 months...I must explain that (P14) **Most time, I do lie because I don't want them to know. I lied by saying I want to pick my child from

			school or I say I am going somewhere with my husband and my boss is very nice, he will give me chance (P15)
	Adherence to medication	Liberty to take medication at work	*I don't take the container with me (to work)…I will tell him so that I will be free (P03) * I always attend to lots of people that may not allow me to take my drugs and I may forget. So when I know that, I will put it (medication) on my table (P04).
		Difficulty adhering to treatment	*I always attend to lots of people (at work) and I may forget (P03)
Management/control of HIV disclosure	Lying about [their] positive status		*Some people do ask me and I say I am ill and feeling uncomfortable in my stomach (P03) *a woman approached me and said why do you use drugs every day and I said we ladies always need to take care of ourselves (P03)

			*I would tell my direct boss that I am going to my normal clinic that you know I am Asthmatic and this weather is not good for Asthma patients so let me go on time before it gets out of it. So he said no problem that I should go (P05)
	Previous known illness	He knows I was sick sometimes ago	*my boss didn't know but he knows I was sick sometimes ago, so I told him they said I am now their patient and that every month, I must come for check-up (P08) * Because they know I have Asthma before and I used to use inhaler...They are now seeing that it's that asthma that… but me I know it's not Asthma (P05) * I will say I want to go for check-up...they already know I have BP (P11)
	Hiding medication package	Don't display the original container at workplace	* I don't take the container with me…if someone should recognise it, that means, he/she has it (P04)

			* And if you are taking your drug normally…they will be asking you what. This drug is for what, why taking it… Then you have to be lying for one thing or the other, at least. (P05) *I have never taken my drugs at work; I use it 6am and 6pm (P14)
	Curiosity of work colleagues	They want to know the drugs I take, They can't ask me	* Yes [they ask questions], you know its office work, we take drugs, Ha, do you have headache, why are you taking drugs for. It's a normal thing to take drugs but they want to really know what happens to you, you are taking drugs for (P05) *They said, Ha, why is it that all the time, have it not stopped; its more than 3 years. I said it's their job to keep checking it until...we all need check-up at least 6 months. So when I told them that, they stopped saying things about the matter (P08)

			*No one can ask me such. There are so many conditions and almost everyone has a medication he/she uses in the morning. If you are not on high blood pressure drugs…some people had to use it every day that's why no one cares to know the type of drugs you take (P10)
	Absent from work	Not going to work	*It's possible they tell another person and that it was the reason why I am not at work (P13) *I may go to work early about 7:30 to do what I needed to do and sign, then leave but I won't return till the next day (P17)
	False disclosure	False disclosure of other less stigmatised condition	*I have Asthma before and I used to use inhaler, someone cannot say because of the HIV, I used inhaler…They are now seeing that it's that asthma that… but me I know it's not Asthma (P05)

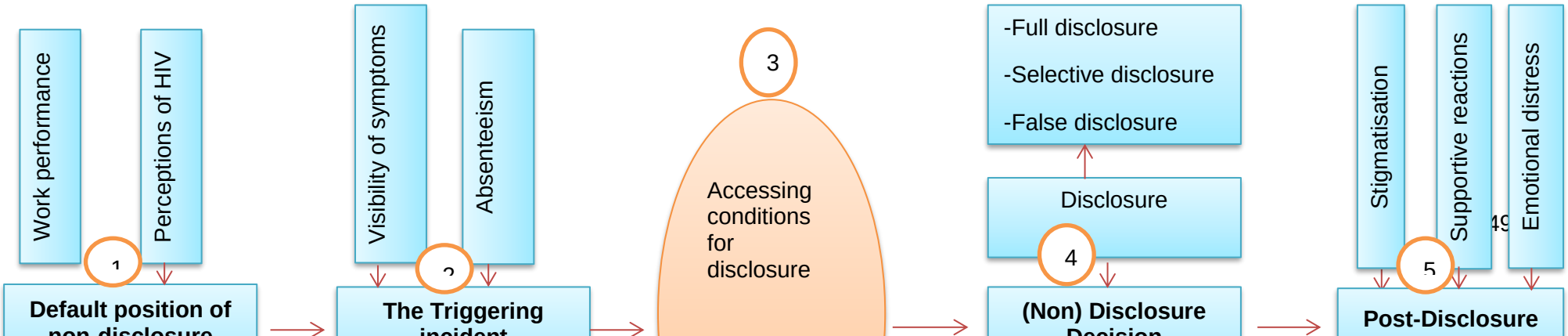
			*I rang my boss on Saturday that I won't be coming to work on Monday that I was sick and he asked if no problem, I said I had little malaria (P15)
	Specified reasons for going for hospital appointment	Going for check-up	*Whenever I want to request for permission, I always say I am going for check-up. That's how I cope at work (P08) *[I will tell them] I am going for the care, for the healthcare or for check-up (P09) * I collect my medication once a month and when it's time to go, I inform my colleague in the office that I am going for check-up; I tell them I am going for check-up. They will not know the type of check-up but I know within me (P10) * I will say I want to go for check-up. That's it (P11) * I say I am going for check-up, could you please give me chance (P12)

			* I will say I am going for check-up but I don't tell them what I go there for except for my wife, no one knows anything (P16) * I inform my boss here in Xx that we work together …that tomorrow is my check-up and they would say, no problem (P17)
	Unspecified reason for appointment	Going somewhere	* I can say, my boss, I won't come tomorrow, I have somewhere to go (P12) *So at work place, I may say I want to go to town… so I don't ever tell anyone that I am going to hospital, I have never because I must explain that (P14) *Most time, I do lie because I don't want them to know. I lied by saying I want to pick my child from school or I say I am going somewhere with my husband and my boss is very nice, he will give me chance (P15)

			* At work, I request for permission that I want to get somewhere and they will give me the opportunity (P16)
	Working hard	Take my job with all seriousness	*If I say I am going for check-up, no one can say anything because I don't play with my job and [I work] with all seriousness (P10)
Management of Status	Access to treatment	Easy access to treatment	*I am a data clerk, I have the files with me, I will just take my card and submit it and collect my drugs, no one will know (P02) *I didn't tell him about my condition because it will get to a stage and it will be like, 'every time, what is really your type of condition?' (P03)
	Suspicious of status	Suspicious of status	* Before, I am always suspicious but now God has helped me. That used to happen but now I don't do that again (P03)
Future disclosure	Planning	Thinking of telling him	*I have been thinking that I needed to tell him (P03)

Fear	Fear of future disclosure	Fear of future disclosure	*but I am not sure the kind of person he is, maybe he will expose me outside
	Fear of suspicion	They will be suspicious	* If I am going every month to collect it, they will be suspicious and asked what I go there for, every month (P07)
	Avoid suspicion	I must explain when its frequent	*If I tell them I want to go to hospital, they understand I may want to visit someone but between the space of 2 months, I told them the same, so I don't ever tell anyone that I am going to hospital, I have never because I must explain that (P14)
Anticipated consequences of disclosure	Trust	Lack of trust	If I tell him, he may use if against me (P03)

Appendix 2d: Final framework derived from the findings on the decision-making process of HIV disclosure in the workplace among people living with HIV/AIDS



Appendix 3: Themes developed

Appendix 4: Informed consent

Informed consent form

The study explores the impact of HIV disclosure in the workplace among people living with HIV/AIDS in Nigeria.

Before taking part of this research, could you please read the following statements carefully and sign a tick next to each statement:

Statements		Signature
1.	I have read and understood the information about the study, as provided in the Participants Information Sheet.	
2.	I have been given the opportunity to ask questions about the study.	
3.	I voluntarily agree to participate in the project.	
4.	I understand that I can withdraw at any time without giving reasons and that I will not be questioned on why I have withdrawn.	
5.	I understand that any information I provide will be treated with complete confidence and my name will not be identified with any information provided.	
6.	I am happy to be interviewed and for the interview to be audio recorded.	
7.	I understand that the information collected from me will be used only for academic purposes.	

8.	I understand that the researcher and supervisors will be the only people who will have access to the data from this study.	
10.	I agree to sign and date this consent form.	

Participant:

_____ _____ _____

Name of Participant Signature Date

Researcher:

_____ _____ _____

Name of Researcher Signature Date

Fọọmu Ifowosowopo

Iwadi na n ṣawari ikolu ti ifihan HIV ni iṣẹ laarin awọn eniyan ti o ngbe pẹlu HIV ati Arun Kogboogun Eedi ni Nigeria. Ṣaaju ki o to gba apakan ninu iwadi yii, jọwọ o le ka awọn ọrọ wọnyi ni iṣọju ki o si fi ami si eyin alaye kọọkan

Awọn Alaye		Ibuwọlu
1.	Mo ti ka alaye nipa iwadi naa, o si ye mi yeke bi a ti pese ninu Iwe Alaye.	
2.	A ti fun mi ni anfani lati beere awọn ibeere nipa iwadi naa.	
3.	Mo fi inu didun gba lati ṣe alabapin ninu iṣẹ naa.	
4.	O ye mi pe mo le yọ kuro nigbakugba laisi ikun sinu ati pe a ko ni bi mi lori idi ti mo fi yọ kuro.	
5.	O ye mi pe eyikeyi alaye ti mo pese yoo ni itọju pẹlu igboya pipe ati pe orukọ mi ko ni je didamo pẹlu alaye eyikeyi ti a pese.	
6.	Inu mi dun lati ni ijomitoro oro ati fun ijomitoro oro lati jẹ ohun ti a gbasilẹ ninu fonran.	
7.	O ye mi pe alaye ti a gba lati ọdọ mi yoo je lilo fun awọn ẹkọ nikan.	
8.	O ye mi wipe oluwadi ati alakoso yoo jẹ awọn eniyan nikan ti yoo ni aaye si esi lati inu iwadi yii.	
9.	Mo gba lati fowo si fọọmu yi.	

Olukopa:

_____ _____ _____

Oruko Olukopa Ibowolu Detii

Oluwadi:

_____ _____ _____

Oruko Oluwadi Ibowolu Deti

Appendix 5: Ethics Approvals a, b & c

Appendix 5a: Letter of Approval from the Nigeria Ministry of Health, Oyo State

TELEGRAMS..... TELEPHONE.....

MINISTRY OF HEALTH
DEPARTMENT OF PLANNING, RESEARCH & STATISTICS DIVISION
PRIVATE MAIL BAG NO. 5027, OYO STATE OF NIGERIA

Your Ref. No. .....
All correspondence should be addressed to the Honourable Commissioner quoting
Our Ref. No. AD 13/ 479/ 553

May, 2015

The Principal Investigator,
University of Ibadan

Attention: Adeuyi Dorcas
Ethical Approval for the Implementation of your Research Proposal in Oyo State

This acknowledges the receipt of the corrected version of your Research Proposal titled: "Disclosure Among People Living with HIV/AIDS in Nigeria: Consequences and Implications in the Workplace".

2. The committee has noted your compliance with all the ethical concerns raised in the initial review of the proposal. In the light of this, I am pleased to convey to you the approval of committee for the implementation of the Research Proposal in Oyo State, Nigeria.

3. Please note that the committee will monitor closely and follow up the implementation of the research study. However, the Ministry of Health would like to have a copy of the results and conclusions of the findings as this will help in policy making in the health sector.

4. Wishing you all the best.

Signature & Date

Sola Ricardo (Dr).
Director, Planning, Research & Statistics
Secretary, Oyo State, Research Ethical Review Committee

Appendix 5b: Letter of Approval from Bowen University Teaching Hospital (BUTH), Ogbomoso, Oyo State, Nigeria

BOWEN UNIVERSITY TEACHING HOSPITAL, OGBOMOSO

(Formerly Baptist Medical Centre)

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BUTH Research Ethics Committee
Registration No: **NHREC/12/04/2012.**

20th April, 2015.

Ms. Dorcas Adeoye
Institute for Health Research,
University of Bedfordshire,
Luton, UK.

Dear Dorcas,

Re: Ethics Approval of the Study Titled 'DISCLOSURE AMONG PEOPLE LIVING WITH HIV/AIDS IN NIGERIA: CONSEQUENCES AND IMPLICATIONS IN THE WORKPLACE"

An expedited consideration of above research submitted to the committee for review was carried out by the Chairman and one other acting on behalf of the entire committee.

We found no step contained therein which contravenes safeguards for studies involving human subjects.

The study is hereby approved as outlined in the proposal submitted.

Should there be any reason to change any step in the protocol, a written clearance must be sought and obtained from the Ethics Committee before implementing the change.

The approval takes effect from 1st September 2015 and lapses to 31st December 2015.

At the end of data collection the Ethic Committee should be notified in writing that the data collection has been concluded.

Kindly make available a copy of your findings so it can be included in the Ethics Library.

Yours faithfully,

Dr. A. Adeniran
Chairman BUTH, Research Ethics Committee.

Appendix 5c: Letter of Approval from the Institute for Health Research, University of Bedfordshire

University of Bedfordshire
Institute for Health Research
Putteridge Bury
Hitchin Road
Luton
Beds LU2 8LE

27 April 2015

Dorcas Adeoye
Student number: 1222613

Dear Dorcas Adeoye

Re: IHREC Application No: IHREC483

Project Title: Disclosure among people living with HIV/AIDS in Nigeria: Consequences and implications in the workplace.

The Ethics Committee of the Institute for Health Research has considered your revised application and has decided that the proposed research project should be approved subject to the satisfactory responses being incorporated into a revised protocol which will be kept on file by the Committee and used as your final protocol.

Please note that if it becomes necessary to make any substantive change to the research design, the sampling approach or the data collection methods a further application will be required.

Yours sincerely

Dr Yannis Pappas
Head of PhD School, Institute for Health Research
Chair of Institute for Health Research Ethics Committee

Appendix 6: Public indemnity insurance by the University of Bedfordshire

Hasilwood House
60 Bishopsgate
London EC2N 4AW
Tel: 020 7847 8670
Fax: 020 7847 8689

TO WHOM IT MAY CONCERN

20th July 2015

Dear Sir/Madam

THE UNIVERSITY OF BEDFORDSHIRE
AND ALL ITS SUBSIDIARY COMPANIES

We confirm that the above Institution is a Member of U.M. Association Limited, and that the following cover is currently in place:-

PROFESSIONAL INDEMNITY

Certificate of Entry No.	UM063/02
Period of Cover	1 August 2015 to 31 July 2016
Limit of Indemnity	£5,000,000 any one claim and in the aggregate except for Pollution where cover is limited to £1,000,000 in the aggregate.
Cover provided by	U.M. Association Limited

If you have any queries in respect of the above details, please do not hesitate to contact us.

Yours faithfully

Susan Wilkinson
For U.M. Association Limited

ISO 9001

U.M. Association Limited
Registered Office: Hasilwood House, 60 Bishopsgate, London, EC2N 4AW
Registered in England and Wales No. 2731799

Appendix 7: The lessons learned from the pilot study

Objectives	What I planned	What I did	What I learnt
Testing data collection tool	Use of the interview schedule as structured	Used interview schedule as structured.	• Use of interview schedule as structured reduces the flow of the interview
	Use of technology for the interview such as audiotape, computer, encrypted USB, phone	• Use of audiotape for recording interviews • A secured computer for imputing daily events and transcript • Phone calls to follow-up on recruitment	• Audiotape needs to be charged & tested before the start of the interview • It is easy to rely solely on technology • It is a valuable tool that needs regular update & development
Personal development and training	The use of reflective diary or field note	• Use of field notes to keep record of event and other issues during data collection	• The field note is useful in writing and analysing reflective report • Helps to understand & improve the event surrounding each interview • A way of keeping records of participants' observation • To reflect on my perception of the event
Recruitment and access	Meet with potential participants during their appointment	The use of a gatekeeper to access potential participants	• The use of a gatekeeper or unit staff protects confidentiality

			especially for people that refuse to participate • Empowers the participant to make self-decision without seeing the researcher • Prevent keeping accurate number of people that refuse to participate • Meeting potential participant gives more opportunity to answer any questions • Timing of the information
	Use of advert, email, phone, hospital records & snowball method	Use of Head of the unit, unit staff and snowball method	• Trust in the system • Confidentiality • Timing of the information • Email or phone only works best when personal contact already established • Hospital records Vs. ethics approval limitation

Appendix 8: The study findings on the prevalence of disclosure, outcomes and factors associated with disclosure

Summary of the included studies on disclosure						
Author(s) name	Disclosure recipients	Length of time of disclosure since diagnosis	Rate of Disclosure	Recipients' reaction after disclosure (positive)	Recipients' reaction after disclosure (Negative)	Reasons/factors/attitudes associated with disclosure
Amoran (2012)	Mainly their sexual partner	Disclosure ranges btw 1 day to 2yrs after knowing their status.	50.9%	Support	__	Family type, marital status, education, knowledge, Anticipated partners' support for disclosure.
Salami, et. al. (2011)	Spouses;47 (18.6%). 52 (20.6%) to members of social network. 46 (18.2%) to relatives. 5 (2%) friends and 2 (0.8%) to work colleagues.	More than 6 months	39.5%	Acceptance 25 (9.9%)	Sadness 77 (30.4%); surprise 37(14.6%)	The knowledge of partners' status, Gender differences, Marital status, Type of Marriage, Occupation, Duration of treatment, confidentiality during consultation.
Olagbuji (2011)	Husband, family members, persons	Not stated	88%	Supportive (74%); indifferent (6.8%)	Quarrelsome (19.2%).	Not stated

	outside family, religious leaders					
Ezegwui, et. al. (2009)	Husband 82 (92.1%); Mother 13 (14.6%); Mother-in-law 2 (2.25); Priest 10 (11.2%); Sister 18 (20.2%)	Less than 6months to 3 years	96.7%	Positive outcomes: Economic/financial support 46 (51.7%); Emotional support 52 (58.45); Social support 21 (23.6%); spiritual support; and others such as understanding from partners and family	Negative outcomes such as stigma 37.1%, blame 23.6%; rejection by family 18.0%, abandonment 14.6%; violence/assault 7.9%; ill-treatment from partners 6.7%, one woman reported divorce (1.1%)	Marriage (close relationship), trust, knowledge of HIV
Sagay, et. al. (2006)	500 (89%) have disclosed to partners; 63.3% have disclosed their status to someone other than partners. Disclosure to siblings,	160 (28.2%) less than 6 month, 159 (28%) 6-12month, 241 (24.5%) more than 12months	Not specified	Of 430 partners were supportive 86.9%; 5.7% were indifferent	6.7% were quarrelsome and abusive and 1% was violent. Overtime, out of 493, 103	Knowledge of partners' status, length of diagnosis

	parents, in-laws, close friends, and some require help of healthcare professional (39.6%)				(20.9%) were quarrelsome and abusive; and few cases of violence report were from negative partners.	
Sadoh and Sadoh (2009)	Majority husbands/partners 45 (78.95%). Of this, 5 (8.77%) parents, 3(5.26%) sisters, 4(7.02%) pastors. Secondary disclosure: parents 16 (28.07%), to sisters 5(8.77%), pastors 6(10.53%), mother-in-law 1(1.75%).	___	57 (91.94 %)	Financial support by parents; moral support by sisters; moral support by pastors & mother-in-law.	Some partners were unhappy	Financial inability is associated with disclosure to partners, breastfeeding.
Dankoli, et. al. 2014	36.8% spousal disclosure, mother=18.7%;	HIV diagnosed less and more than a year	97.5%	Spiritual assistance= 2.1%; adopt safer	__	Age, education, gender, marital status, employment, length of

	sister=13.5%; Brother=9.8%; Friend=7.3%; father=5.7%; child=3.6%; others=2.6%; Boss=2.1%; pastor/imams=0%.			sexual practice=10.1%; sympathy=13.2%; support=74.1%		diagnosis. Excused from difficult work=0.5%
Okereh, et. al. (2013)	Spouse: Self-disclosure 87.7%; third party disclosure 12.3%.	Less than 6month disclosure after diagnosis=93.0 %; more than 6month=7.0%.	Not specified	Care and love 30 (52.6%); supportive (70.2%); do not cause conflicts 63.2%.	Stigma/discrimination 52.6%; fear of divorce by 27(47.4%); rejection 27(47.4); Abusive/quarrelsome (29.8%); Disclosure causing conflict 36.8%.	Disclosure changes relationship with recipient=86.0%; it does not change relationship 14%.
Adebayo, et. al. (2014)	Sexual partners; 260 (88.7%)	___	75.6%	__	___	Marital status: Odds of married to disclose their status is 12 times compare to singles.

Titilope, et. al. (2011)	Spouses/sexual partners	__	61.5%	Disclosure do not bring rejection, regret or other adverse effect of disclosure (96.7%)	____	Marriage, Education, Gender.
Adekanle, et. al. (2015)	Partners or family members	__	___	- 14.3% reported that partners' awareness of their HIV status had strengthened their marital relationship	-Sex deprivation 62%; - partner's rejection of condom use 74.3%; Fear of becoming infected (85.7%), illness (75%), pregnancy (50%), partners having other sexual partners (28.6%) and blaming the women for their	Age ($p < 0.001$), high level of education ($p < 0.001$), partners' awareness of respondents' HIV status ($p < 0.001$) and nulliparity ($p < 0.001$).

					positive status (85.7%) were the reasons given for being sexually deprived by their partners. - Lack of confidentiality by their healthcare workers 23%.	
Ujah, Ezechi & Ohihoin (2015)	Sexual Partner	Not stated	3712 (83.7 %)	Not stated	Not stated	HIV positive status of a sexual partner, level of intimacy, poor socioeconomic status, previous pregnancy termination, past sexual partner, and level of education
Ogoina, et. al. (2015)	Sexual partners	____	100%	-89(72.4%) reported positive initial partner reactions to disclosure	-34(27.6%) reported negative initial partner reaction which include: feeling sad/	Positive initial partner reactions were associated with prior post-test counselling-(Odds ratio [OR]-6.5, 95% Confidence interval [CI]-1.3-

					unhappy (n=14), indifference (n=11), Quarrelsome/ abusive partner (n=7), and break up of marriage (n=2)	31.6-p=0.02), >35years-(OR-5.8, 95% CI-1.6-20.9-p=0.008) and being healthy at time of disclosure-(OR-7.8, 95% CI-1.7-35.4-p=0.008). -Patients receiving ART were significantly more likely to report a positive or supportive subsequent partner reaction than those who are ART naive (OR=13.5, 95% CI 2.7-67.9, p=0.002). Patients with one lifetime sexual partner were significantly more likely to report positive or supportive subsequent partner reactions than those who had two or more lifetime sexual partners (OR=8.5, 95% CI

Adebiyi & Ajuwo (2015)			50.7%			-Marriage, adopting safer sex, Knowledge of partners' status and for emotional support

Appendix 9: Showing prevalence, reasons and factors associated with nondisclosure

Author(s)	prevalence of non-disclosure	Reasons for non-disclosure	Reasons/factors associated with nondisclosure
Amoran (2012)	Not clear	Fear of: separation or divorce (37.7%), Labelled as a bad person (5.0%), being isolated by partner (25.5%); fear of physical abuse (9.2%); others (4.2%). Not living together with partner due to work distance (6.1%).	_____
Salami, et. al. (2011)	153 (60.5%)	____	_____
Olagbuji (2011)	12%	Fear of spread of information (57.8%), stigmatisation (53%) and deterioration in the relationship with the spouse (47%), abandonment, accused of infidelity.	Significantly associated with nulliparous and unmarried women.

Ezegwui, et. al. (2009)	3.3%	Fear of blame, avoiding conflict, confidentiality	____
Sagay (2006)	10.7%	Fear of negative outcomes and misconception about transmission.	Knowledge of partners' status
Sadoh and Sadoh (2009)	5 (8.06%)	Pressure from family, fear of stigmatisation, divorce/ end of relationship, infidelity accusation.	Marital status; single mothers were least likely to disclose their status, breastfeeding choice.
Titilope, et. al. (2011)	38.5%	Fear of rejection (65%); loss of intimacy (32.5%); stigmatisation (21.3%); loss of economic support (15%) & threat of personal wellbeing (12.5%)	Safer sex, multi-sexual partners counselling
Adekanle, et. al. (2015)	8%	___	___

Ujah, Ezechi & Ohihoin (2015)	620 (16.7%)	___	____
Adebiyi & Ajuwo (2015)	49.3%	Fear of abandonment (14.9%), separation from partner (12.8%), fear of stigma (10.6%), death of partner (10.6%) and lack of trust in partner (5.3%).	-Non-disclosure to all sexual partners was more (62.3%) among respondents who did not know their partners' status than among those who knew (28.8%).

Appendix 10: Meta-analysis showing rate of disclosure

	Data		Fixed Effect			Compute Tau ^2		Random Effects				
Study	Rate ratio (ES)	Variance	Variance Within	Weight	ES * WT	ES^2*WT	WT^2	Variance within	Variance Between	Variance Total	WT	ES*WT
Amoran	0.509	0.2499	0.2499	4.00	2.035	1.035	16.0	0.2499	0.044	0.2939	3.402	1.73
Salami	0.186	0.1513	0.1513	6.61	1.228	0.228	43.7	0.1513	0.044	0.1952	5.122	0.95
Olagbuji	0.880	0.1060	0.1060	9.44	8.300	7.300	89.1	0.1060	0.044	0.1499	6.669	5.87
Ezegwui	0.913	0.0794	0.0794	12.60	11.500	10.500	158.6	0.0794	0.044	0.1234	8.105	7.40
Sagay	0.893	0.0957	0.0957	10.45	9.333	8.333	109.3	0.0957	0.044	0.1396	7.161	6.39
Sadoh	0.789	0.1662	0.1662	6.02	4.750	3.750	36.2	0.1662	0.044	0.2102	4.758	3.76
Dankoli	0.975	0.0246	0.0246	40.63	39.600	38.600	1650.5	0.0246	0.044	0.0686	14.578	14.21
Adebayo	0.756	0.1842	0.1842	5.43	4.106	3.106	29.5	0.1842	0.044	0.2282	4.382	3.31
Adebiyi	0.508	0.2499	0.2499	4.00	2.031	1.031	16.0	0.2499	0.044	0.2939	3.402	1.73
Ujah	0.837	0.1364	0.1364	7.33	6.134	5.134	53.7	0.1364	0.044	0.1804	5.542	4.64

Adekanle	0.230	0.1768	0.1768	5.66	1.298	0.298	32.0	0.1768	0.044	0.2208	4.529	1.04
Titilope	0.615	0.2367	0.2367	4.22	2.599	1.599	17.8	0.2367	0.044	0.2807	3.562	2.19
Sum				116.377	92.914	80.914	2252.356				71.212	53.219

Combined values for fixed effect		Compute Tau ^2				Random Effects	
Effect size	0.798	Q	6.733			Effect size	0.747
Variance	0.009	Df	11.0			Variance	0.014
Standard error	0.093	Numerator	4.267			Standard error	0.119
95% lower limit	0.617	C	97.024			95% lower limit	0.515
95% upper limit	0.980	Tau squared	0.044			95% upper limit	0.980
Z-value	8.613					Z-value	6.306
p-value (1-tailed)	0.00					p-value (1-tailed)	0.00
p-value (2-tailed)	0.00					p-value (2-tailed)	0.00

Heterogeneity

(I2)

-63.3845024

If < 0 = 0

Interpreting Tau squared (Higgins 2003)

0% = No heterogeneity

25% = Low heterogeneity

50% = Moderate heterogeneity

75% = High heterogeneity

Appendix 11: Meta-analysis showing supportive responses

	Data	Fixed Effect	Compute Tau ^2	Random Effects

Study	ES	Variance	Variance Within	Weight	ES * WT	ES^2*WT	WT^2	Variance within	Variance Between	Variance Total	WT	ES*WT
Salami	0.53	0.2490	0.2490	4.02	2.136	1.136	16.1	0.2490	0.076	0.3248	3.079	1.64
Olagbuji	0.74	0.1925	0.1925	5.19	3.842	2.842	27.0	0.1925	0.076	0.2683	3.727	2.76
Ezegwui	0.67	0.2222	0.2222	4.50	3.000	2.000	20.3	0.2222	0.076	0.2980	3.356	2.24
Sagay	0.87	0.1141	0.1141	8.77	7.615	6.615	76.9	0.1141	0.076	0.1899	5.267	4.58
Sadoh	0.93	0.0622	0.0622	16.07	15.000	14.000	258.3	0.0622	0.076	0.1380	7.246	6.76
Dankoli	0.43	0.2451	0.2451	4.08	1.755	0.755	16.6	0.2451	0.076	0.3209	3.116	1.34
Ogoina	0.72	0.2000	0.2000	5.00	3.618	2.618	25.0	0.2000	0.076	0.2758	3.626	2.62
Adekanle	0.14	0.1224	0.1224	8.17	1.167	0.167	66.7	0.1224	0.076	0.1982	5.045	0.72
Oareh	0.70	0.2093	0.2093	4.78	3.353	2.353	22.8	0.2093	0.076	0.2851	3.508	2.46
Sum				60.572	41.486	32.486	529.667				37.970	25.117

Combined values for fixed effect		Compute Tau ^2				Random Effects	
Effect size	0.685	Q	4.072			Effect size	0.661
Variance	0.017	Df	8.0			Variance	0.026
Standard error	0.128	Numerator	3.928			Standard error	0.162
95% lower limit	0.433	C	51.828			95% lower limit	0.343
95% upper limit	0.937	Tau squared	0.076			95% upper limit	0.980
Z-value	5.330					Z-value	4.076
p-value (1-tailed)	0.00					p-value (1-tailed)	0.00
p-value (2-tailed)	0.00					p-value (2-tailed)	0.00

Heterogeneity (I2)

-96.4442842

If < 0 = 0

Interpreting Tau squared (Higgins 2003)

0% = No heterogeneity

25% = Low heterogeneity

50% = Moderate heterogeneity

75% = High heterogeneity

Appendix 12: Quality Appraisal of the included studies

Author (s) and Year	Sampling strategy	Eligibility criteria described	Statistical power calculated	Number of participants Pre/post	Response rate	Control group	Participants matched	Analytical procedure	Data collection instrument-pilot	Data collection instruments-reliable/ validated	Consent procedure, Ethical clearance
Amoran (2012)	Convenience sampling	Inferred	No	637/637	N/M	No	N/A	X^2 and logistics regression model	Yes	Test-retest reliability and face validity	Consent procedure described, ethical clearance obtained
Salami, et. al. (2011)	Purposive sampling	Yes	No	253/253	N/M	No	N/A	Spearman correlation coefficient	No	Not tested	Consent procedure described, ethical clearance obtained
Olagbuji (2011)	Purposive sampling	Yes	Yes	166/179	Yes:92.7%	No	N/A	Students' t-test & Fisher's exact test	No	Validated (not specified)	Consent procedure described, ethical

											clearance obtained
Ezegwui, et. al. (2009)	Purposive sampling	No	No	92/92	N/M	No	N/A	Frequency/ percentage	No	No tested	Consent procedure described
Sagay (2006)	Purposive sampling	Yes	No	570/570	N/M	No	N/A	Frequencies/percentage	No	Test-retest reliability and content validity	N/M
Sadoh & Sadoh (2009)	Purposive sampling	Yes	No	62/62	N/M	No	N/A	Fisher's exact test; one-way ANOVA	No	Not tested	Consent procedure described

Continued

Dankoli, et. al. (2014)	Systematic random sampling	Yes	Yes	198/200	Yes	No	N/A	Bivariate analysis and multiple logistic regression	No	Test-retest reliability and face validity	Consent procedure described, ethical clearance obtained
Okareh, et. al. (2013)	Purposive sampling	Yes	No	57/57	Yes	No	N/A	Frequency distribution table, graph.	Yes	Test-retest reliability with coefficient of 0.73	Consent procedure described, ethical clearance obtained
Adebayo, et. al. (2014)	Purposive sampling	Yes	Yes	578/578	Yes	No	N/A	X^2 and Logistic regression 5% level of significant.	Yes	Test-retest reliability.	Consent procedure described, ethical clearance obtained
Titilope, et. al. (2011)	Convenience sampling	Yes	No	499/499	N/M	No	N/A	Test of significance	No	Not tested	Consent procedure described, ethical

											clearance obtained
Adekanle, et. al. (2015)	Convenience sampling	Yes	No	122/122	Yes-100%	No	N/A	A binary logistics regression model; p-value <0.05	Yes	Test-retest reliability	Consent procedure described, ethical clearance obtained
Ujah, Ezechi & Ohihoin (2015)	Convenience sampling	Yes	No	4435/4435	N/M	No	N/A	Frequency distribution, univariate analysis, multivariate logistic regression	No	No	Consent procedure described, ethical clearance obtained
Ogoina, et. al (2015)	Convenience sampling	Yes	No	123/123	100%	No	N/A	Chi-Square, multivariate unconditional logistics regression	No	Test-retest	Consent procedure described, ethical clearance obtained

Adebiyi and Ajuwon (2015)	Systematic random sampling	Yes	Yes	122/122	N/M	No	N/A	Chi-square, the Student's t-test and ANOVA	Yes	Test-retest	Consent procedure described

Appendix 13: Abstract of the published paper 1- systematic review study

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Available online at www.sciencedirect.com

Public Health

journal homepage: www.elsevier.com/puhe

Review Paper

Factors influencing HIV disclosure among people living with HIV/AIDS in Nigeria: a systematic review using narrative synthesis and meta-analysis

*D.I. Adeoye-Agboola**, *H. Evans*, *D. Hewson*, *Y. Pappas*

Institute for Health Research, University of Bedfordshire, United Kingdom

ARTICLE INFO

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Nigeria

ABSTRACT

Objectives: To critically review, appraise and evaluate quality of evidence on HIV disclosure among people living with HIV/AIDS (PLWHA) in Nigeria, and to identify a possible gap in knowledge on HIV/AIDS and disclosure.

Study design: A systematic review using narrative synthesis and meta-analysis.

Methods: MedLine, PsycINFO, PubMed Central, Scopus and CINAHL were searched. Data were extracted with the use of spread sheet. An analysis of heterogeneity was performed for the disclosure rate and the presence of a supportive reaction from partners. A meta-analysis was performed for the disclosure rates to sexual partners, with data available for all ten studies.

Results: Ten studies met the inclusion criteria. The outcomes show that HIV disclosure of sero-positive status is most common between spouses or sexual partners than disclosure to relatives/family members, friends, pastor/Imam or work colleagues/employers. The participants in most of these studies are women, and amongst the most influential factors on disclosure are gender, anticipated outcome, marital status and knowledge of partners' status. Some studies reported non-disclosure as a way of limiting stigma. Almost all of the studies highlighted that there is fear of stigma and social exclusion associated with disclosure.

Conclusion: This review discusses the overall experience of HIV disclosure on the management of the disease and barriers to disclosure. We found that PLWHA in Nigeria disclosed to at least one person within their social networks. Stigma is still a major consideration for PLWHA who experience a range of misconceptions around HIV transmission. The findings of this study may inform local policies and plans for improving the PLWHA quality of life. Targeted policies to increase disclosure of sero-positive status and reduce stigma may facilitate disease prevention. The methodological rigour of the included studies was appraised low.

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http://dx.doi.org/10.1016/j.puhe.2016.02.021
0033-3506/

Appendix 14: Abstract of the published paper 2- The implications of invisible symptoms

The author's institutional affiliation: Institute for Health Research

University of Bedfordshire

Putteridge Bury

Hitchin Road, Luton

LU2 8LE

Abstract

Visibility of symptoms can affect the way or whether the affected person would disclose their disease to their professional networks. The study explored the invisible symptom of HIV on the decision to disclose or not, in the workplace among employed people living with HIV/AIDS (PLWHA) in Nigeria. Face-to-face in-depth interviews with semi-structured interview schedule as a tool were conducted among 20 employed PLWHA who had been diagnosed with HIV for more than six months. It was found that an invisible condition allows PLWHA to plan disclosure appropriately in the workplace. Non-disclosure was mostly reported in the workplace, and this was linked to their invisible symptoms. This study has provided an in-depth knowledge on how an invisible condition may prevent disclosure in the workplace and its impact on access to treatment.

Keyword: invisible symptoms, HIV/AIDS, employment, people living with HIV/AIDS, Nigeria

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Appendix 15: HIV-specific laws

Annex: HIV-specific laws in sub-Saharan Africa

Country	Title of HIV-specific law	Year of adoption
1 Angola	Lei No 8/04 sobre o Virus da Immunodeficiëncia Humana (VIH) e a Sindroma de Immunodeficiëncia Adquirida (SIDA)	2004
2 Benin	Loi No 2005-31 du 5 Avril 2006 portant prévention, prise en charge et contrôle du VIH/SIDA	2006
3 Burkina Faso	Loi No 030-2008/AN portant lutte contre le VIH/SIDA et protection des droits des personnes vivant avec le VIH/ SIDA	2008
4 Burundi	Loi No 1/018 du 12 Mai 2005 portant protection juridique des personnes infectées par le Virus de l'Immunodéficience Humaine et des personnes atteintes du Syndrome Immunodéficience Acquise	2005
5 Cape Verde	Loi No 19/VII/2007	2007
6 Central African Republic	Loi 06.030 de 2006 fixant les droits et obligations des personnes vivant avec le VIH/SIDA	2006
7 Chad	Loi No 19/PR/2007 du 15 Novembre 2007 portant lutte contre VIH/SIDA/IST et protection des droits des personnes vivant avec le VIH/SIDA	2007
8 Comoros	Loi No 14-011/AU du 21 avril 2014, relative aux droits des personnes vivant avec le VIH et leur implication dans la réponse nationale	2014
9 Congo	Loi No 30 - 2011 du 3 juin 2011 portant lutte contre le VIH et le SIDA et protection des droits des personnes vivant avec le VIH	2011
10 Côte d'Ivoire	Loi No 2014-430 du 14 juillet 2014 portant régime de prévention, de protection et de répression en matière de lutte contre le VIH et le SIDA	2014
11 Democratic Republic of Congo	Loi No 08/011 du 14 Juillet 2008 portant protection des droits des personnes vivant avec le VIH/SIDA et des personnes affectées	2008
12 Equatorial Guinea	Ley No 3/2005 sobre la prevención y la lucha contra las infecciones de transmisión sexual (ITS), el VIH/SIDA y la defensa de los derechos de las personas afectadas	2005
13 Guinea	Ordonnance No 056/2009/PRG/SGG portant amendement de la loi L/2005/025/AN du 22 Novembre 2005 relative à la prévention, la prise en charge et le contrôle du VIH/SIDA en République de Guinée	2009, amended HIV Law of 2005
14 Guinea-Bissau	Loi No 5/2007 du 10 septembre 2007 de la prévention, du traitement et du contrôle du VIH/sida	2007
15 Kenya	HIV and AIDS Prevention and Control Act, No 14 of 2006	2006
16 Liberia	An Act to Amend the Public Health Law, Title 33, Liberian Code of Laws Revised (1976) to Create New Chapter 18 Providing for the Control of Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS)	2010
17 Madagascar	Loi No 2005-040 du 20 Février 2006 sur la lutte contre le VIH/SIDA et la protection des droits des personnes vivant avec le VIH/SIDA)	2006

18 Mali	Loi No 6-028 du 29 Juin 2006 fixant les règles relatives à la prévention, à la prise en charge et au contrôle du VIH/ SIDA	2006
19 Mauritania	Loi No 2007-042 relative à la prévention, la prise en charge et le contrôle du VIH/SIDA	2007
20 Mauritius	HIV and AIDS Act, No 31 of 2006	2006
21 Mozambique	Lei No 12/2009, estabelece os direitos e deveres da pessoa vivendo com HIV e SIDA, e adopta medidas necessárias para a prevenção, protecção e tratamento da mesma	2009
22 Niger	Loi No 2007-08 du 30 Avril 2007 relative à la prévention, la prise en charge et le contrôle du Virus de d'Immunodéficience Humaine (HIV)	2007
23 Senegal	Loi No 2010-03 du 9 avril 2010 relative au VIH/SIDA	2010
24 Sierra Leone	The National HIV and AIDS Commission Act of 2011	2011, amended HIIV Law of 2007
25 Tanzania	HIV and AIDS (Prevention and Control) Act, No 28 of 2008	2008
26 Togo	Loi No 2010-018 du 31 Décembre 2010 modifiant la loi No 2005 – 012 du 14 Décembre 2005 portant protection des personnes en matière de VIH/SIDA	2010, amended HIV Law of 2005
27 Uganda	HIV Prevention and Control Act of 2014	2014